A CROSS-CASE ANALYSIS OF MIGRANT CHUUKESE FAMILIES IN HAWAIʻI AND THEIR CHILDREN WITH SPECIAL NEEDS

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DEDICATION

Dear reader,

Since you are opening these pages, I assume you have some interests in learning something about disabilities and families of children with disabilities. Thank you for sharing this interest with me for I, too, have some vested interest in learning, writing, and teaching about families and disabilities and how the two act upon, and affect, each other. I also have spent a good portion of my life, not just studying and working with issues of disabilities, but also living the life of a person with significant disabilities. On June 1, 1980, 37 years ago, a nasty fall from a rock plunged me and my family into a lifetime experience with disabilities. But, I must confess I do not know what being "disabled" means to me and my family. I have never quite learned the significance of that term.

However, the only sure thing is that my life and the life of my family has changed because of the label and challenges that come with being "disabled." In 2011, when I entered the doctoral program at the University of Hawai‘i-Mānoa, my family was struggling with the process of losing my sister, Kutelia, who had been diagnosed with cancer the year before, and her son Jon, who was born with hydrocephalus. He was in his early teens. He was smart and fun to be around but, in the end, he had missed his mother so much that we could not successfully keep him alive.

So, when Kutelia and Jon passed away in 2011, our family became distraught because we couldn't help them. We could not save them from cancer and an illness related to hydrocephalus. Through this 5-year process of living in Hawai‘i and working in healthcare and community advocacy, I have come to appreciate the strength and resiliency of families of children with

disabilities. I realize that they are strong and happy when they are able to manage and overcome their challenges and provide their children with positive loving care.

These families of children with disabilities, like my sister and her son, moved from their home islands to Hawai‘i for the hope of accessing better, lifesaving, and life-sustaining healthcare. They showed great resilience in the face of many challenges in their daily lives. Like my sister and her son, they made those around them stronger and happier in dealing with their illnesses and disabilities. We, the family members, continued to love and appreciate their contribution to our lives.

I dedicate this study to my sister Kutelia and my nephew Jon and the three families and their special children, for everything that they have taught me about life and disability. To all families who have the experience of raising a member or child with disabilities or special needs, may you rise on the wings of your dreams and bless us with your joy, laughter, and happiness.

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Finally, I want to thank all of my relatives and friends near and far, at home in the islands and in other homes in newer places. The memories and the souls of the departed, the refreshed love and joy with every newborn, the assuring warmth of smiles, laughter and nurturing helping hands of familial bodies, and the sustained wisdom and character of the elders, continue to nourish and guide me each and every day. Thank you for your support, your faith in God, and your willingness to carry me through this significant part of our lives.

ABSTRACT

Citizens of the Compact of Free Association (COFA) nations of Micronesia are the newest ethnic migrant group in Hawai‘i. This relationship is born out of the long history of the geopolitical relationship between the COFA nations (the Republic of Palau, Federated States of Micronesia, and the Republic of the Marshall Islands) and the United States. Currently, COFA citizens have open access to the country but their unique immigration status as unqualified migrants limits their ability to access social safety net support programs. Using a combination of Family System Theory, Family Resilience Theory, and Family Quality of Life Theory, this study also utilizes indigenous Chuukese concepts of travel to investigate the background, experience, and cultural-charged perceptions of social services by three Chuukese families of children with special needs in Hawai‘i. Data were collected and analyzed from individual semi-structured interviews and focus group discussions, primary and secondary documents, and prolonged observations. The study conclusions showed that these families maintain a strong connection with their networks of support. Despite facing challenging barriers in Hawai‘i, these families were resilient and reciprocate by helping others and giving back to their networks and communities. Their children’s disabilities were not seen as signs of weakness and diminished dreams. These families thrive because of such challenges, not in spite of them.

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CHAPTER 1. INTRODUCTION

Problem Statement

Chuukese citizens from the Federated States of Micronesia (FSM) compose the largest group of Compact of Free Association (COFA) migrants in the United States, including Hawai‘i. The community’s size, along with barriers related to their access to social services, and the lack of related research, combine to create a pressing social justice issue for Chuukese families of children with disabilities or other significant health needs.

Barriers include Chuukese immigration status as COFA citizens, which limits eligibility and access to social services that would otherwise support families of children with special needs and other social safety net services (Riklon, Alik, Hixon, & Palafox, 2010; Shek & Yamada, 2011). Additionally, Chuukese families face language and cultural barriers in navigating their daily lives in Hawai‘i. The combined effects of these barriers on the outcomes for Chuukese families of children with disabilities must be carefully assessed to gain a better understanding of the unique challenges facing this new group (Hagiwara, Yamada, Tanaka, & Ostrowski, 2015). The prevailing stereotypes and racism against Micronesian citizens in Hawai‘i also affect the way families of children with special needs, access support services.

Although none of the current research addresses the specific needs of children with disabilities and their families’ experiences in Hawai‘i, there is enough information from both primary and secondary sources to build a foundational narrative about the experience of Chuukese and other Micronesian families of children with special needs. This narrative demonstrates a critical need for further research about the experiences and outcomes of Chuukese children with special needs living in Hawai‘i.

Background to the Research

FSM Children with Special Needs

According to FSM Maternal and Child Health Department (MCH), nearly 1,160 children were registered in their Children with Special Health Care Needs (CSHCN) database in 2011. The bulk of those children (714) were from Chuuk (see Figure 1). Chuuk had the highest number of children with Speech and Language impairment (549), yet only 6 students were recorded in the Specific Learning Disabilities (SLD) category. The fact that there are only 6 identified SLD students is unusual because the other FSM states with much smaller populations recorded high numbers of students in the same category: Pohnpei (546), Yap (158), and Kosrae (116). This indicates a likely inconsistency in the way data are collected and reported across the four states of the FSM.

Disability Policy and Services in the FSM

The FSM congress has developed public policy to ensure children with special needs receive education and related services, such as the 2009 FSM Disability Policy. This policy outlines broad guidelines for providing services to the nation's population of children with special needs. The nation also signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations Information Centre Canberra, 2016). The FSM Public Law 14-8 requires that children with special needs be provided with Free and Appropriate Education. This law mirrors the U.S. Individuals with Disabilities Education Act (IDEA), which provides funding for education and related services for children with special educational needs. According to the FSM Division of Special Education, out of 1,830 students served by special education in the school year 2010-2011, 756 were from Chuuk State. In 2012, the FSM Special Education Division provided services to nearly 1,900 children from the ages of

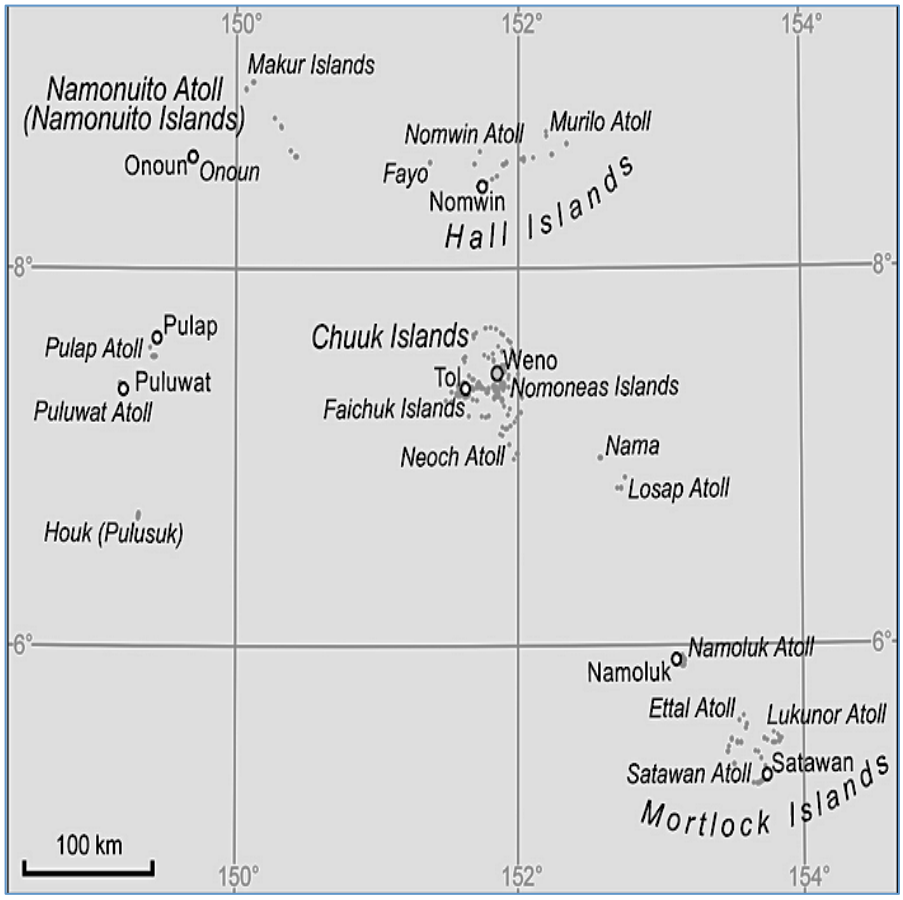

Figure 1: Chuuk State (also known as Truk) consists of several island groups: Chuuk Atoll, Nomwisofo, Hall Islands, Namonuito Atoll, Pattiw, Eastern Islands, and Mortlock Islands.

3-21. While data after 2012 are unavailable, this year-over-year increase suggests that either the population of children with special educational needs is growing at this high rate or the child-find activity had increased.

Although Chuuk State has a U.S. federally funded special education program, there are chronic problems such as lack of certified, trained teachers to serve the special needs population in the islands. An audit report on the performance of the Special Education Program in Chuuk from 2006-2008 cited a lack of compliance by the department in many areas including teacher certification. Though both FSM law and the grant require that teachers be certified or at least have an associate degree, 75% of all special education teachers in Chuuk did not have a two-year level degree and only 20% of those without a degree were currently enrolled in a degree program (Office of National Public Auditor, 2009).

Furthermore, while the FSM National Standards define the minimum quality teacher certification to be an Associate of Arts or Associate of Science degree, it does not specifically state that the degree must be in education. There is no special education program available through the local community college. The Associate of Arts is in general education and includes only one introductory course in exceptionality.

The geography of Chuuk State is another barrier to meeting the needs of students with disabilities. The islands are divided into five regions, including a lagoon area that covers approximately 820 square miles of expansive ocean. Chuuk State Department of Education has established 94 elementary and secondary schools across the state. Of the 94 schools, 91% are accessible only by boat or ship. This contributes to the great difficulty in system and administrative management, as well as improving instructional delivery through professional development services. In addition, students cannot be reliably or regularly transported, which

makes it impossible to create specialized services in one school to serve students from a broader region. There are no disaggregated data on Chuukese parental satisfaction with the services received for their children with special needs. However, FSM national statistics reported a downward trend in the percentage of parents indicating satisfaction in these services from 93% in 2008, to just 54% in 2011 (CSHCN, 2013).

Micronesian Diaspora in Hawai‘i

At the request of the Federated States of Micronesia (FSM) National Government, Hezel and Levin conducted a survey to determine the number of Micronesian citizens living abroad as well as their reasons for migrating (*Survey of FSM migrants in the United States, Guam and CNMI,* 2010). According to the report, a sizeable number of Chuukese families had migrated to the United States to seek education, healthcare, and economic opportunities (2010). The data indicated that, of the 7,948 FSM citizens living in Hawai‘i, over half (4,204) were from Chuuk (see Table 1). This figure is consistent with the general population distribution of the FSM. With a population of 48,654, Chuuk State is the most populated of the four FSM states and accounts for nearly half of the nation’s total population of 102,843 (FSM Census, 2010). Of the 4,204 Chuukese people who migrated to Hawai‘i, more than half (2,260) arrived in the nine years prior to the census. Most of the Chuukese population in Hawai‘i, 3,067, is native to Chuuk State. A smaller number of Chuukese people, 698, were born in the United States; 420 of whom were born in Hawai‘i, while the rest came from the continental U.S, Guam, and Commonwealth of Northern Marianas Islands (CNMI). According to Hezel and Levin (2012), The median age of Chuukese migrants is 29.5, which means that the Chuukese population in Hawai‘i is relatively young: birth to 19-year-olds (1382); 20- to 39-year olds (1661); 40- to 59-year-olds (816); and

Table 1

Citizenship of FSM Household Members in Hawai‘i, 2012

Citizenship	Total	Chuuk	Pohnpei	Yap	Kosrae
Total	7,948	4,204	2,193	255	1,296
FSM Citizens	6,193	3,444	1,460	166	1,123
US Citizens	1,755	760	733	89	174

Note: The Chuukese population in Hawai‘i accounted for over half of the total population of FSM citizens living in Hawai‘i in 2012.

60-year-olds and over (345). The vast majority (72%) of the Chuukese population in Hawai‘i is below 40 years old.

These statistics highlight that the migrant Chuukese community is the largest of the Micronesian subgroup and is still growing. The number of Chuukese living in the United States has increased by 544% over the past decade (Advancing Justice, 2014). This figure indicates that the growth rate of Chuukese residents in Hawai‘i is 18 times greater than that of Native Hawaiians.

Ratliffe (2010) discussed the "push and pull" factors that explain why families move from the Compact of Free Association (COFA) nations of Micronesia to Hawai‘i. Push and pull factors are the reasons that compelled migrants to either leave their home land or be drawn to a new country (Lee, 1966). A push factor is a situation from which a migrant is leaving, such as inadequate medical services. A pull factor is the perceived benefit in the new location, such as effective and appropriate medical treatment. The "push" factor, from their home islands, is the need for better opportunity to get basic social services (Ratliffe, 2010). "Family reason" is the most cited reason (1,146) for Chuukese who moved to Hawai‘i, followed by "employment" (939), "education" (939), and "medical reasons" (632), according to Hezel and Levin (2012). Others have critically examined the disparity in funding support and access to reliable medical services (Hagiwara, et al., 2015; Riklon et al, 2010; Shek & Yamada, 2011; Yamada & Pobutsky, 2009.) Unfortunately, many Chuukese residents in Hawai‘i are faced with a myriad of challenges and inequities that span social, political, and economic arenas (Shek & Yamada, 2011). The Chuukese migrants most affected by these circumstances are the most vulnerable: children with disabilities and their families.

COFA Citizen Access to U.S. Social Services

Chuukese families in Hawai‘i have experienced a major shift in accessing safety net programs in the social services. Between the establishment of the Compact of Free Association in 1986 through 1996, the COFA citizens living in Hawai‘i and throughout the United States jurisdictions were classified as lawful “Qualified Aliens” (Riklon et al, 2010) and were generally covered under the legal constitutional concept of “Permanent Residence Under the Color of Law” (PRUCOL), which gave them legal access to all social safety net programs (Cousins, 2014; Riklon et al, 2010; Shek & Yamada, 2011). However, in 1996, the U.S. Congress reformed the welfare program, and COFA citizens were re-categorized as “Non-eligible Aliens” and excluded from the list of exempt eligibility groups for benefits such as Medicaid and Social Security. Currently, Chuukese and other COFA citizens (not including the U.S.-born) living in the United States, are not eligible for Social Security Supplemental Security Income (SSI), Medicaid, Temporary Assistance for Needy Families (TANF), Children Health Insurance Program (CHIP), and Supplemental Nutritional Assistance Program (SNAP). These are the general safety net programs designed to help low income families across the United States (see Table 2).

In 2009, after keeping COFA citizens on State-run public health insurance program (MedQUEST), the State of Hawai‘i proposed separate coverage for them called Basic Health Hawai‘i (BHH) with significantly reduced healthcare benefits (Shek & Yamada, 2011). In November 2014, after a series of court cases, the State officially announced that it would move about 7,500 COFA citizens off of its MedQUEST program onto the Hawai‘i Health Connector, Hawai‘i’s version of the Marketplace created under the Affordable Care Act (ACA, 2010). This has created confusion in the Micronesian community as these citizens are now being enrolled in

Table 2

COFA Immigrants and Public Benefits Eligibility

Programs	Federal Eligibility Status
Social Security Old Age, Survivors, Disability Insurance	Eligible
Social Security Supplemental Security Income	Generally Ineligible
Medicaid	Generally Ineligible except for Aged, Blind, Disabled and Pregnant
Emergency Medicaid	Eligible
Medicare	Eligible
Children's Health Insurance Program (CHIP)	Generally Ineligible
Temporary Assistance for Needy Family (TANF)	Ineligible
Supplemental Nutrition Assistance Program (SNAP)	Ineligible
School Lunch Programs	Eligible
Section 8 Housing Federal Rent Subsidies	Eligible

Source: Legal Aid Society of Hawai‘i and National Immigration Law Center, 2015

private insurance with co-payments and other related costs that they are unable to afford (Inada-Hagiwara, 2014).

In addition to the eligibility issues, Chuukese families face other barriers to accessing services for their children with disabilities living in Hawai‘i. As one of the newest ethnic immigrant groups, parents often find it difficult to negotiate barriers such as language access and different social expectations (Harry 2008; Ratliffe, 2010). Economic outcomes are also a major challenge, especially with limited job opportunities and an extremely high cost of living in Hawai‘i. Finally, recent policy in both the federal and state social services has increased the challenges for this new immigrant group to attain better healthcare for their families.

Language access is a major barrier for new immigrant groups, such as people from Micronesia, in struggling to leverage social services (Hawai‘i Appleseed, 2011; Pobutsky et al. 2010; Shek & Yamada 2011). Hawai‘i language access law guarantees the right of Chuukese-speaking migrants to be provided with language interpreters. However, the Appleseed survey (2011) pointed out numerous instances when Chuukese citizens were denied the service. In addition to language barriers, there are cultural misunderstandings that lead to challenges with Chuukese families accessing services for their children with disabilities. Heine (2003) noted that there was great confusion and mismatch of expectations between COFA parents and school officials. Ratliffe (2010) discussed the important role of family obligations among Micronesians and how much these obligations are misunderstood by school personnel.

Community Perceptions and Stereotypes of Chuukese Migrants in Hawai‘i

Stereotypes and anti-Micronesian rhetoric have created a volatile racist climate for Chuukese and other Micronesians in Hawai‘i. The Hawaii Appleseed Center for Law and Economic Justice compiled a report documenting many of the injustices inflicted on the

Chuukese and Micronesians who reside in Hawai‘i (*Broken Promises Report*, 2011). As documented in the *Broken Promises* report, the Internet and radio waves have become a medium for racial epithets that perpetuate disturbing images of Micronesians as "lazy, opportunistic leeches who scrupulously prey on the social services system" (p. 15). Such images likened Chuukese and other COFA citizens as "invasive cockroaches," "dirty," and "stupid" (p. 15). Women donning traditional Chuukese skirts and dresses reported being treated with disrespect and malice. Chuukese and other Micronesian school children have become the butt of racial and ethnic jokes; they have been bullied by their classmates, and negatively stereotyped.

These stereotypes and prejudices by the broader Hawai‘i community about Chuukese migrants have impacted their experiences with service providers as well as the perceptions of teachers toward Chuukese families of children with disabilities (*Broken Promises Report, 2011;* Hagiwara, 2015).

Lack of Research on Chuukese Children with Special Needs in Hawai‘i

There is an evolving base of research literature on Chuukese and other Micronesian immigrant family experiences in Hawai‘i (Falgout 2010; Heine, 2002; Iding, Cholymay, & Kaneshiro, 2007; Kaneshiro & Black, 2012; Ratliffe 2010, 2011; Talmy, 2010). Most of this research makes connections between these immigrant groups' experiences, nuances of their cultural backgrounds, and the mismatches that result from these competing expectations. However, none of the existing research literature addresses the experiences of Chuukese children with disabilities or significant health needs and their families.

Purpose of Study

The purpose of this qualitative study is to explore contributing factors to the challenges Chuukese families of children with disabilities face in Hawai‘i. This study also identifies the

solutions that these families have created and utilized to address their challenges. This will help establish a clear picture of these families' resiliency and their concepts of their overall family quality of life. This research also examines their motivations, values, and daily experiences.

Another purpose of this study is to investigate Family Quality of Life (FQOL) outcomes for Chuukese families of children with significant health needs and disabilities living in Hawai‘i. This will help build an in-depth understanding of the push and pull factors behind these families' decisions to move to Hawai‘i and the challenges they encounter. This study will also examine how these families navigated and developed solutions to address these issues and challenges.

Research Questions

The primary research aim is to address the overall experiences of Chuukese families and their children with disabilities who live in Hawai‘i. The primary research question is, "What are the experiences of recent Chuukese migrant families of children with disabilities living in Hawai‘i?"

To address this primary research question, I have developed the following sub-research questions:

Research sub-question A**:** What are the factors that motivate Chuukese families of children with disabilities and special health care needs to move to Hawai‘i?

Research sub-question B**:** What are some of the challenges and barriers Chuukese families, who live in Hawai‘i and have children with disabilities and special health care needs, face in their daily lives?

Research sub-question C**:** How do Chuukese families, who live in Hawai‘i, feel about the overall quality of supports and services that are available to their children with disabilities and special health care needs?

CHAPTER 2. REVIEW OF THE LITERATURE

This chapter will provide a brief history of Chuuk and how its past influences the present expectations about the role of government in providing health, education, and social services. Next, this chapter will provide an overview of the background of Chuukese families of children with disabilities, including their socio- and geo-cultural backgrounds and their access to social services. In this discussion, it is essential to underscore the unique historical and contemporary relationship between Chuuk (along with rest of the FSM nation) and the United States. Finally, this chapter will discuss the three theoretical underpinnings that pertain to special education and families of individuals with disabilities: Family System Theory, Family Quality of Life, and Family Resilience.

History of Chuuk

Geography

Chuuk consists of 46 square miles of land and is the most populous state of FSM, with approximately 50,000 citizens. Weno island is the state capital and FSM's biggest city. Chuuk is situated in the middle of the FSM, and encompasses a total land area of 49.2 square miles, and includes seven major island groups (FSM Board, 2017). In addition, there are 14 major volcanic islands in the lagoon and numerous atolls. Chuuk is divided into five distinct regions, including: Faichuuk, Northern Nomwuneas, Southern Nomwuneas (volcanic islands in a large lagoon), Mortlocks (11 islands southeast of the lagoon), and Pafong, Nomwunweito, and Pattiw (see Figure 1).

Pre-Colonial Period

Prior to the colonial period, Chuuk never had a unified hierarchy of traditional rulers. Its traditional networks (*machew*) and extensive clan system (*ainang*) defined relationships and engagements from warfare, trade, tribute, marriages and even the act of accessing basic resources (Hezel, 2014). The lineages are matrilineal with senior women on each island controlling clan resources such as land, taro fields, and fishing rights (Goodenough, 1951). According to Hezel (1992), the ainang (clans) on each island were divided into eterenges (groups of extended families). These groups are the basis of traditional units of relationships in Chuuk. The English word *family* has been appropriated to define the nuclear family unit when necessary in this study.

Anthropologist Manuel Rauolchz (2011) further explained the clan system and value of clan connections in the movement of Chuukese through their home islands and beyond:

> Beyond the realm of the nuclear family and lineage providing individuals with a sense of security and belonging, the matri-clans of these highly mobile Chuukic-speaking islanders were felt to provide this same sense of security and providence on a meta level, beyond just the local island or village of residence, uniting a network of persons over vast distances of open ocean. These people, when members of the same clan, all shared a common identity, an ideal sense of common origin and belonging together. This sense of belonging together has been perceived as being one of natural belonging and togetherness and is visibly demonstrated through the sharing, corporate holding, and use rights to the most important natural resources available such as land (islands) and reefs. (p. 53)

Chuukese travelers sailed throughout the islands establishing trade connections to expand their resources. A system of political, economic, and religious ties called *sawei* connected all the inhabited islands in the Chuuk lagoon and atolls, outer atolls of Yap and Palau, to the Gagil

district in the main island of Waap (Yap). In ancient times this was called a tribute system (Metzgar, 2006). Traditional navigation and the related seafarer knowledge and practice made this movement among networks possible (Falgout, 2012; Metzgar, 2006; Peter, 2010). Even though contemporary government practice has reorganized Chuuk into seven regions (see Figure 1), these clans continue to have a strong influence over family relations, tribute, and resource allocation.

European Influence

During the period of European exploration of the Pacific, French geographer Domeny de Rienzi coined the term "Micronesia" in 1831 (Hanlon, 1999). Micronesia, occupying the equatorial and northern Pacific region, includes the entities of Kiribati, Nauru, Republic of the Marshall Islands, Federated States of Micronesia, Republic of Palau, Guam, and the Commonwealth of Northern Mariana Islands (see Figure 2). *Chuuk* (mountains) is the traditional delineation of the mountainous lagoon islands from its surrounding atoll islands generally grouped as *Fenappi* (sandy islands). The name Chuuk is a convenient, but inaccurate, label invented to describe the grouping and regionalizing of the islands spread throughout the central Micronesian region in the northern Pacific Ocean. In the German colonial period, from 1893 through 1914, the region was spelled Truk as an approximation of Chuuk; this spelling carried forward through the United States trusteeship period (Rayphand, 2014).

In 1521, Spanish explorer Ferdinand Magellan made the first documented contacts between European and indigenous Micronesian islanders, the indigenous Chamorros of Guahan (Guam) (Hezel, 1994). Spain laid claims to the Mariana Islands as well as the Caroline archipelago (Palau, Yap, Truk, Pohnpei, which was labeled Ponape and included Kosrae or "Kusae."). The first recorded European contact with Chuuk was in 1565 when Spanish Captain

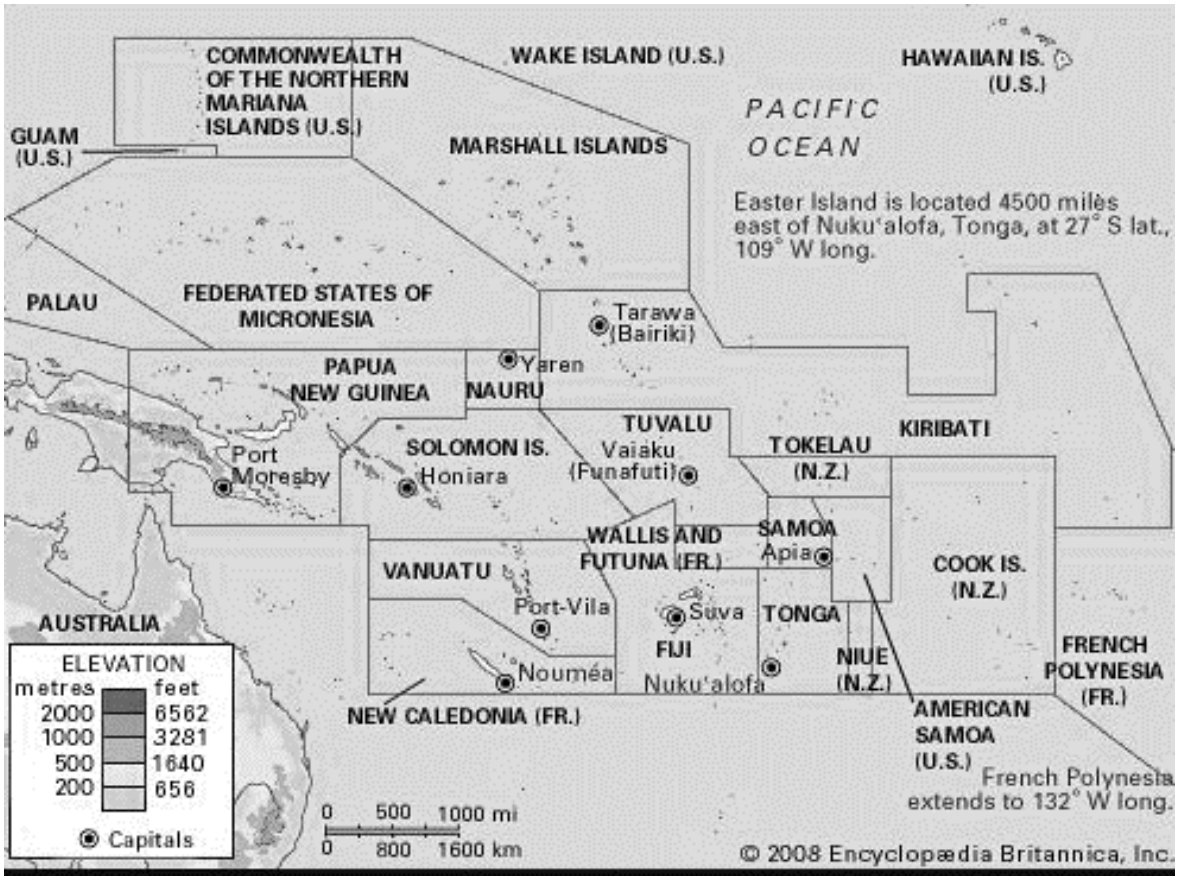

Figure 2: Map of Pacific Region. Source: Image downloaded from Google Image. Map of the Pacific Region (Encyclopedia Britannica, 2010)

Alfonse de Arellano sailed his ship, the San Lucas, into the Chuuk lagoon (Hezel, 1994). According to Hezel, after escaping the islanders' pursuit through the lagoon, Arellano lost some of his crew to the warriors of Pulap, 200 miles west of the lagoon. As a result, Chuuk earned a reputation for being violent toward explorers in those days:

> Don Luis de Torres, a Spanish official on Guam who had contact with canoe voyagers from the central Carolines, cautioned the commander of a French naval expedition that Chuuk's reputation among its fellow islanders was no better than among foreign seamen. "The natives of Truk have a bad reputation even among their own compatriots," he remarked. (Dumont d'Urville: cited in Hezel, 1973 p.66)

According to Hezel (1973), this perception of the Chuukese as violent and hostile toward foreigners had earned them a reputation and label of "dreaded Hogoleu."

Spain's rule in Chuuk and Micronesia was predominantly for religious purposes. Actual religious conversion was limited, though, due to the negative view of the islanders by European captains. So, except for a few recorded sightings of the islands by passing ships, the islands were relatively untouched by European explorers. Chuukese and other island travelers made up for that lack of contact through their own voyages to Guam, which was a major transit point for foreign ships traveling to and from the Orient. These encounters brought foreign items and curious stories of the Europeans into the world of the islanders.

After the Spanish-American war in 1898, Germany took control of the Marshall and Caroline Islands to intensify its economic activities (Hezel, 1984). Through the efforts of German and other European traders, prolonged contact and exchanges with islanders transformed the lifestyle of the islanders. The *sawei* networks existed until the early 1900s when the German

colonial government outlawed them (Hezel, 1994). Germany brought predominately secular changes, by establishing schools and hospitals.

Missionaries, American pastors and local teachers, from the American Board Commission on Foreign Missions (ABCFM), also began to establish their influence in Chuuk by establishing schools for the purpose of promoting biblical literacy. Trading and commerce influenced the islanders' sense of time and work, and also commoditized land, as foreign traders bought land and fishing rights that would traditionally be controlled by the clan system. Land registration, through individual chiefs, transformed the access to these resources. Furthermore, the German colonial administrator facilitated the new western economic expansion by requiring islanders to build roads, bridges, and canals as massive public projects.

With rampant Western diseases ravaging Islanders to the critical point of massive depopulation in places like Guam, Pohnpei, and Kosrae, Islanders were afraid of encounters with outsiders until the missionaries and administrators provided relief through Western medical intervention. Hezel (2010) described the devastation caused by the introduction of new diseases:

> Missionary sources report outbreaks of one disease or another every few years: influenza was rampant in 1856, 1871, 1874, and 1879; while measles outbreaks occurred in 1861 and 1894. As a result, Pohnpei's population at the end of the century was estimated at about 5,000, half of what it had been in 1840 before the heavy toll that foreign disease had exacted from the people of the island. (p.12)

In Kosrae, Rev. Benjamin Snow reported that between1855-1858 the population of the island of Kosrae "show[ed] a decline during that period from 1,106 to 747, for an annual population loss of 11 percent" (Hezel, 2010, p.13). Snow attributed this population loss to a

series of epidemics. These changes in health and education laid the foundation for the future of government-based social services in the islands.

Japanese Period

Germany lost its colonial possessions after the country's defeat in World War I (WWI). Japan then took over colonial administration of the islands under the League of Nations. Japan accelerated the pace of development in the islands from 1907 under its policy of *Nanyo* or South Sea expansion (Peattie, 1989). By the time World War II broke out in 1938, Japan was at the height of its economic development in Micronesia. Land registration intensified and local governmental units were organized in villages and islands under a system of appointed "flag" chiefs. Intermediate and vocational schools were created to promote public education, mostly to acculturate the Islanders to Japanese lifestyle and labor practices. The government also established small hospital units in the main islands.

Relationship between Chuuk, FSM, and the United States Trust Territory of the Pacific Islands

The political relationship between the United States and the Federated States of Micronesia began after World War II when Japanese colonial rule collapsed, and the region was attached to other islands such as Guam and Saipan, into one entity, the Trust Territory of the Pacific Islands (TTPI), under the United Nations (Charter of the United Nations, 1945). The Trust Territory encompassed the vast Pacific region that stretched from the Philippine Sea to the International Dateline. The United Nations granted administrative control of the TTPI to the United States in 1947. The U.S. TTPI, one of 11 UN-mandated trusteeship arrangements, was unique in that it carried with it subtext of being a "strategic trust." This meant that it allowed for the United States to administer the trusteeship program of developing the islands in a manner

that was consistent with its strategic military needs. The islands were divided into six districts with the High Commissioner's office at the head of the TTPI located in Saipan. The districts were Northern Marianas, Palau, Yap, Truk, Pohnpei, and Marshall Islands.

During the first half of the trusteeship era, 1947-1961, the United States did not pay much attention to promoting socio-economic development in the islands. Critics of the U.S. colonial rule in the islands characterized that period as "rust territory," depicting the United States' neglect of the islands.

This colonial relationship benefited the United States by granting unlimited access to millions of square miles of ocean space for military purposes as well as shipping routes. For example, in the late 1940s and 1950s, the United States detonated 67 atomic bombs on the Marshall Islands as part of its nuclear testing program in the TTPI. The health effects of radioactive exposure included thyroid and other cancers, as well as birth defects (i.e., babies born without recognizable features) and were linked directly to the nuclear testing program in the Marshall Islands during the period when the United States administered the TTPI (Palafox, 2010).

However, U.S. policy changed under President John F. Kennedy's administration and subsequently with President Lyndon Johnson's social service expansion. During the Kennedy and Johnson administrations, there was an increase in the annual budget of the territorial government over a five-year period, from $1.2 to $6.8 million, an increase of 467%. This expenditure increase was mainly in the governmental and social services area such as education and health. With growing urbanization, public schools and hospital-based healthcare systems were created as people moved into the district centers to work for the government and to attend schools.

In 1960, the General Assembly of the United Nations adopted the Declaration on the Granting of Independence to Colonial Countries and Peoples, to address these nuclear impacts and other injustices in colonized lands. This declaration called for decolonization around the world, including to U.N.-established Trust Territories, such as the TTPI. It led to the establishment of several decolonization approaches, including complete independence, free association, and self-governance as a commonwealth. In the 1970s, the TTPI began the decolonization process, with the various Pacific Island entities opting for different pathways toward self-determination. For example, Saipan, Tinian and Rota joined together to become the Commonwealth of the Northern Mariana Islands. Palau and the Marshall Islands each negotiated a separate Compact of Free Association with the United States. Yap, Chuuk, Pohnpei, and Kosrae joined together in a multilingual, multi-cultural block, called the Federated States of Micronesia, which then negotiated a collective Compact of Free Association (see Figure 3).

Compact of Free Association

Signed in 1986, the Compact of Free Association (COFA) agreements established free entry into the United States for citizens of the Federated States of Micronesia (FSM) and Republic of the Marshall Islands (RMI), and later in 1994, the Republic of Palau (COFA, 1986). The Compacts with the FSM and RMI expired in 2001, were extended to 2004, and then amended for the period from 2004 to 2023.

Citizens from COFA nations were granted the right to live and work in the United States with no visa or labor certification and no limitations of stay. In return, United States citizens are allowed similar privileges in the COFA nations. The United States also was granted access and exclusive military control over a million miles of sovereign territories in the northern Pacific,

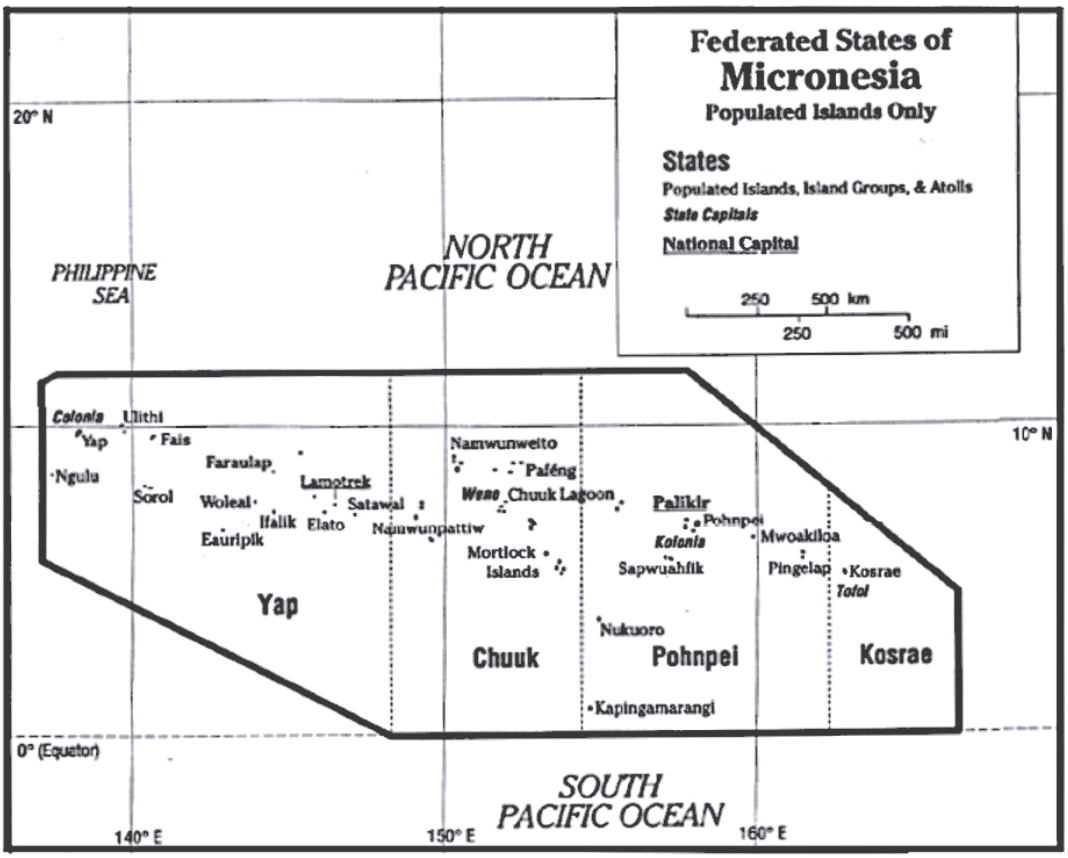

Figure 3: Map of the Federated States of Micronesia. This figure illustrates the four states that make up the Federated States of Micronesia. From east to west, the states include Kosrae, Pohnpei, Chuuk, and Yap (U.S Department of the Interior, 2000).

providing a base for military operations, in exchange for military protection for the COFA nations.

In addition, the COFA agreement called for the FSM to receive financial assistance that would help the country realize socio-economic development and self-reliance. However, a report by the South Pacific Commission (2008) observed that the reality was different:

> Under the Compact, the United States pledged 1.3 billion dollars in aid during the period 1986 to 2001. However, by the mid-1990s, it had become apparent that a variety of obstacles were hindering the pace of development, and that dependence on United States aid was not diminishing at the anticipated rate. (p. 1)

After the initial 15-year funding scheme of the agreement, the FSM and the United States agreed to prioritize education and health services. This agreement and the current funding arrangement—which is designed to reduce operating funding each year by diverting a portion of the package to a trust fund in order to promote self-reliance—is in effect until 2023.

Chuuk State government is partially funded by the COFA agreement, which provides the entire budget of the two largest governmental sectors, education and health. During the global economic downturn in 2008, the FSM economy shrank over four percent. Even though the economy experienced positive growth in 2010 and 2011, the downsizing of the government payroll to meet the Compact decrement fueled a general downward trend. According to a progress report issued for the period 2008-2011 by the FSM National Health & Social Services Division (2012),

> FSM is still relying heavily on outside support for funding, specialized services, and technical assistance…[d]espite the increase in health expenditure, the proportion of the FSM population affected by [Non-Communicable Diseases] NCDs and communicable

> diseases are still high compared to other countries in the region. [And] FSM is still spending much of its limited financial resources outside the country (medical referrals). (p. IV)

This statement underscores the continued problems of the healthcare system in the islands. Yet, the U.S. Government Accounting Office (2006) pointed out that the distribution of the Compact and foreign aid funding is based on a formula that does not consider per capita funding and expenditure. In this formula, states with larger populations like Chuuk, receive the same share of foreign aid packages as the other smaller states. This has resulted in limited funding for health and education services in Chuuk.

Another area where the disparity is critical is in healthcare spending. According to the World Health Organization, Chuuk spent the least amount in healthcare revenue per capita on healthcare 2009 (see Figure 4). While Chuuk government spent $140.00 per capita on healthcare for a population of 54,000 (50.5% of the total F.S.M population of 107,000), Kosrae with a population of 8,000 (7.5% of FSM's population), spent $440.00. The steepest disparity is between how much the United States spent in 2009 per capita on health compared to Chuuk: the United States spent 48 times per capita more than Chuuk.

According to UNICEF (2013), the country's population below the age of 18 was 43 percent of the total population of 102,843. This report cited the latest census data from 2010 and showed a drop of 0.4 percent compared to data from 2000. Although FSM ranked third as the least urbanized country in the Pacific region, Chuuk State's population density is more than twice (2.6 times) the national average. This is indicative of the heavy concentration of Chuuk's population on Weno, the state capital. This urbanization also contributes to poor access to vital resources necessary to maintain positive health outcomes. According to the 2005 Household

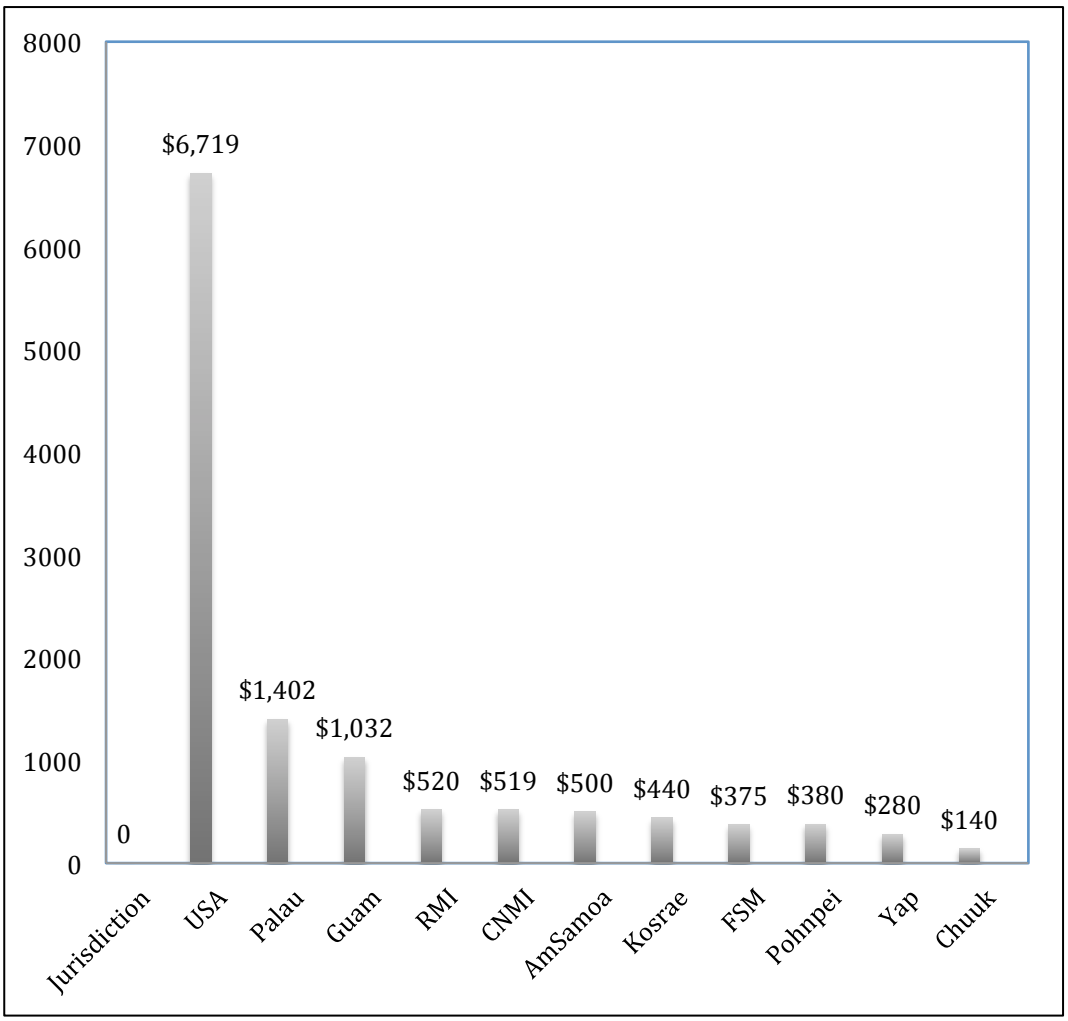

Figure 4. This chart highlights the disparities in per capita healthcare spending when comparing the US and its affiliated Pacific Islands (Riklon et al, 2010.)

Income & Expenditure Survey Analysis Report cited by UNICEF (2013), 30% of the population was living below the country's basic needs poverty line, and 11% lived below the food poverty line and could not afford a minimally nutritious diet. In Chuuk, 12% of its population is within that latter category of nutritional deprivation.

Chuukese Families of Children with Disabilities in Hawai‘i

Chuukese citizens were granted permission under the 1986 COFA treaty to work, study, and receive medical treatment in the United States, without a visa. As legal residents of the United States, they are also required to pay local, state, and federal taxes and were eligible for most of the same public benefits as Americans (COFA, 1985). In 1996, the U.S. Congress amended these policies with the enactment of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA). The ramifications of PRWORA included dismantling public programs and services that were previously available to non-U.S. citizens and COFA migrants. Consequently, the COFA citizens who had agreed to cede their territories to the United States for military control, no longer had access to services that their tax dollars were earmarked to support (*Broken Promises Report,* 2011).

Socio- and Geo-Cultural Background

As one of the newest ethnic immigrant groups living in Hawai‘i, Chuukese families deal with a complex web of challenges that affect their daily lives. These challenges range from chronic healthcare needs, educational gaps, lack of economic opportunity, and language and cultural barriers (Pobutsky et al., 2005). Chuukese families exist on the verge of economic poverty with other low-income marginalized groups. The health conditions of this group are generally dismal with high rates of diabetes and other chronic illness associated with impoverished socio-economic status. While they share many of the challenges of social

inequalities, they also possess unique characteristics, particularly in the issues of fair access to healthcare and effective utilization of services.

In Hezel and Levin's community survey (2012), they noted that FSM citizens in the United States have taken on "the kinds of employment taken by migrants that include entry-level jobs as housemaids, aides in nursing homes, security guards, deliverymen, cashiers at convenience stores and eateries, among other jobs" (p.ii). They also pointed out that half (2.0) of the members of the households, which average 4.0 members, are working. In that survey, 936 claimed "employment" as their primary reason for immigrating to Hawai'i. The survey shows that 1,293 of the Chuukese surveyed were working and earning a median income of $14,045. This is slightly above (1.005%) the Federal Poverty Level (FPL) for Hawai'i in 2012, $13,970. That means that even when many Chuukese are working, they are still struggling to meet their own basic needs, as well as those of their children and families (Hagiwara et al, 2015; Riklon et al, 2010).

Social Risk Factors

The acts of prejudice against Chuukese and Micronesians with reference to language and cultural barriers, treatment for medical conditions, housing, and the judicial system, intersect to create a lifetime of challenges. Negative stereotypes and acts of discrimination are damaging, not only because they impede the proper delivery of services, but also because they serve to perpetuate social and racial epitaphs and acts of hatred against one of the United States' most vulnerable populations (Finch, Koloty, & Vega, 2000; Noh & Kaspar, 2003; Rogers & Dunne, 2010). Perhaps these negative stereotypes are rooted in the unique political relationship between COFA nations and the United States and the associated misconceptions about eligibility for benefits afforded to citizens of these nations.

Political Risk Factors

Although implications of the unique nature of the COFA status for Chuukese and other Micronesians in Hawai‘i have not been thoroughly analyzed, it is still possible to point out obvious ambiguity and problematic outcomes for this population (Johnson, 2012). The COFA agreement allows for open immigration access to the United States for COFA citizens. In effect, COFA citizens are lawfully permitted to establish "habitual residency" within the United States and its jurisdictions, without being citizens and without the need for a work permit or green card (Article IV of Title I, Public Law 99-239). Unfortunately, this unique immigration status has created a situation in which Chuukese citizens living in the United States do not have equal and full protection against discrimination or access to social safety net programs like Medicaid, Social Security Supplemental Security Income (SSI), and Child Health Insurance Program (CHIP) (Hagiwara, Yamada, Tanaka, & Ostrowski, 2015; Serrano, 2014). Additionally, the implications of PRWORA resulted in COFA citizens being removed from Medicaid and other federally subsidized programs (Serrano, 2014).

Furthermore, in 2009 the State of Hawai‘i eliminated COFA citizens' access to the MedQUEST program, which was intended to provide high quality universal access to healthcare for the non-elderly and non-disabled (Shek & Yamada, 2011). The common sentiment of some Hawai‘i political leaders is that Chuukese and other COFA citizens are not the responsibility of the state (*Broken promises,* 2011). Although the state receives $11 million annually from the federal government for what is termed "Compact Impact," officials consider the amount inadequate (*Broken promises*, 2011). In an op-ed piece published in the state's leading newspaper, the *Honolulu Advertiser*, Governor Linda Lingle alleged that federal legislation aimed at providing financial impact compensation for Hawai‘i fell short of addressing "…the

unfair burden on Hawai'i's taxpayers — currently topping $120 million annually — created by the federal government's Compacts of Free Association (COFA), which allow migrants from Micronesia, the Marshall Islands and Palau to live in Hawai'i" (2010, para 13). In its annual report to the U.S. Congress, *Actions Needed to Reduce Fragmentation, Overlap, and Duplication*, the U.S. Government Accounting Office (GAO) countered the arguments of the Hawai‘i, Guam, and CNMI statement of Compact Impact:

> These cost estimates contained [a] number of limitations with regard to accuracy, adequate documentation, and comprehensiveness, affecting the reported costs' credibility and presenting a precise calculation of total Compact Impact on the affected jurisdictions. For example, some jurisdictions do not accurately define Compact migrants, account for federal funding that supplement the local expenditures, or include revenue received from Compact migrants [through taxes]. (p. 2)

Regardless of this GAO report to Congress, the State of Hawai‘i was working to enroll 7,500 COFA citizens, who had previously been using MedQUEST, in the Hawai‘i Health Connector program, the state exchange under the Affordable Care Act (Gill, 2015). The Hawai‘i Health Connecter allows the state to shift the cost of COFA residents' healthcare to the United States Federal Government. Unfortunately, these changes adversely affected COFA citizens by charging them co-payments for medical appointments and services, which further perpetuate the cycle of poverty (HealthyPacific.org, n.d.). Hagiwara and colleagues (2015) confirmed that healthcare costs for COFA citizens were becoming unreachable, "Given the limited resources of some COFA migrants, many were not able to afford these new costs, as under Med-Quest they did not have these fees" (p. 141).

This is just one instance of Chuukese citizens, and other COFA groups, being negatively affected by competing political agendas between federal and state governments in the United States.

Economic Risk Factors

Able-bodied adults are employed to provide needed funds to support the family. Hezel and Levin (2012) reported that of the 7,948 FSM citizens living in Hawai‘i, “family reason” is the most cited motive (1,146), followed by “employment” (939), “education” (939), and “medical reasons” (632). The second, third, and fourth reasons (employment, education, and medical) are all related to the first reason: Chuukese people operate in family units (Ratliffe, 2010). However, Chuukese families in the United States are often displaced when first arriving to the United States. In Hawai‘i, many have no option but to reside in parks, public thoroughfares, or homeless shelters for economic reasons due to the extremely high-cost of housing. The Chuukese people have become part of the increasing poverty gap that exists in the economic margins. Hezel and Levin (2012) reported the median family household income for FSM families was $42,150 for an average household size of four in Hawai‘i, but this is far more than the average household income for those migrants from Chuuk State. The Chuukese median worker’s wage in Hawai‘i was $15,337 in 2012 (Hezel & Levin, 2012). Even if half of the number of household members were working, the total estimate of annual income would be $30,674, still within the low-income poverty range (Medicare, 2012).

Access to Social Services

To comprehend the magnitude of these circumstances, a clearly articulated link must be established between the critical of needs of Chuukese families and the barriers to services. Additionally, this link needs to account for the COFA agreement, which dictates the immigration

status of Chuukese families living in the United States, and their resulting eligibility for social services. Because Hawai‘i medical facilities offer medical treatments like dialysis and chemotherapy that are unavailable in Micronesia, families often relocate to Hawai‘i to ensure healthcare for family members who need those treatments.

Theoretical Underpinnings

This study intersects with two major areas in the study of exceptionality. First, it examines the concept of family structure and especially Family Quality of Life (FQOL) and the crucial role of extended family and community support for families of children with disabilities (Summers, Behr, & Turnbull, 1989). Second, challenges that these new immigrant families from culturally and linguistically diverse (CLD) backgrounds face must be addressed to build successful support for their children with disabilities (Harry, 2008; Kalyanpur & Harry, 1999; Lo, 2010).

The theoretical underpinnings for this study on the Family Quality of Life (FQOL) for immigrant Chuukese families of children with disabilities living in Hawai‘i, rests on the intersection of three approaches: Family Systems Theory (Bowen, 1978); Resiliency Theory (Rutter, 1985); and FQOL theory (Olson & Barnes, 1982). The first of these, Bowen's Family Systems Theory, relies on the family as a unit of analysis, beyond the measure of the individual with disability's personal factors (1978). Next, the Resiliency Theory focuses on families' capacities and strategies in coping and overcoming challenges (Rutter, 1985). Although both Family Systems Theory and Resiliency Theory were first conceptualized in the fields of sociology and psychology, the theories played a significant role in shaping the concept of family-centered involvement in special education (Turnbull & Turnbull, 1997). Last, the theoretical concept of FQOL emphasizes the broader domains of the family's collective perception of

strengths, weaknesses, and outlook on life (Zuna, 2010). The three theories intersect to create the foundational framework for exploring the indigenous Chuukese conceptualization of family, space, and movement. More specifically, this study considers the realm of special education and family outcomes through the tradition of Chuukese families as active agents, who understand and invest in travels and space for group empowerment (Falgout, 2012; Hau'ofa, 1994; Peter, 2000). In summary, this section of the dissertation will map out the conceptual framework at the theoretical conjunction of the Family Systems Theory, Resiliency Theory, and Family Quality of Life. Finally, an indigenous map will underscore and represent perceptions of family and community networks and collaboration within Islanders' tradition of travels.

Family Systems Theory

Family Systems Theory (FST) is an approach outlined by psychiatrist Murray Bowen. FST is often used as an approach for supporting clients with emotional problems, alcoholism (Bowen, 2007) and codependency (Prest & Protinsky, 1993). According to Bowen, FST "assumes that all important people in the family unit play a part in the way family members function in relation to each other…" (2007 p. 115). The focus predicts that changes to any one individual within the family network will affect everyone else in the family. Hence, any meaningful intervention for individuals with issues like alcoholism must consider the whole family in ways that are appropriate and respectful of family structure and protocols. The four major domains of FST are family structure, family interaction, family functions, and family life cycle (Summers, Brotherson, & Turnbull, 1998). Relationships among individuals in the family are critical to understanding the roles and expectations for each individual toward each other and towards the group. These roles and expectations influence how members interact and operate as

these roles, functions, and expectations evolve over time and over the lifespan of the group. What follows is a description of FST as situated within the domain of special education.

According to FST, families are goal-directed, self-correcting, dynamic, and interconnected systems that are influenced by their environment and inherent qualities (White & Klein, 2002). FST shares its core concepts with special education regarding the shift of focus from the individual as an isolated person with a diagnostically determined disability, to a larger system of family connections, which includes the individual with a disability. Wayman, Lynch, and Hanson (1991) stated that FST "focuses on the entire family as it defines itself. Therefore, the context of intervention includes all family members, not just the child with the disability and his or her parents" (p.60). Turnbull and Turnbull (2001) pointed out the ways in which the Individuals with Disabilities Education Act (IDEA) has evolved and increased the role of parents in the special education of their children with disabilities. So, I propose that FST relates to special education by affirming that positive family participation in their children's education can lead to increases in the family's satisfaction with the services and reduced stress and depression.

Chuukese Family System. As noted above, the English term "family" has been appropriated into the Chuukese language to describe the basic or nuclear units within the more extensive Chuukese structure of eterenges*,* the extensive, multi-generational, and inclusive network of kinship (Flinn, 1990, Marshall 1977, Goodenough, 1957). The etrerenges is the sub-section of the extensive clan or ainang lineage. Reflective of this structure, there are no Chuukese words for uncle, aunt, cousins, nephews, and nieces. Chuukese family relationships do not differentiate between primary relationships such as "brothers" or "sisters" and secondary relationships like "cousins." There are only terms for father (sam), mother (inn), brother (pwi), sister (mongoei), and child (nau). One would consider all uncles as "fathers" and aunties as

"mothers." All nephews and nieces are considered one's own children, nau. Furthermore, it is common for children to be adopted by members of the eterenges, the extended families. It is important to differentiate between this locally guided and defined "adoption" and the Western model of adoption. In the Western model, adoption is seen as a removal of the adopted child from a family and there is a delineated breakage of bond from one kinship unit to another. In Chuukese adoption, the child is entrusted to a relative or someone whose relationship is greatly valued. Siblings, other relatives, and also people, who may be from outside the eterenges but are well regarded to be as valuable as a family member, adopt children in these eterenges groups. Therefore, adoption and caring for children within this eterenges kinship is an inclusive mechanism.

In this Chuukese eterenges the roles of the members are shared. The aunts and uncles with equal care and responsibility share the fatherly and motherly duties such as child rearing, discipline, and mentoring. These Chuukese family concepts and functions are consistent with the definition of family roles and responsibilities outlined in Family System Theory.

Resiliency Theory

Resiliency theory (Rutter, 1985) originated as a model for studying outcomes in youth with high-risk social status, focusing on individual development in a longitudinal approach (Werner, 1993; Werner & Smith, 1982). In this theoretical framework, the element of challenge or risk factors is a necessary component of resilience (Walsh, 2003) such as overcoming abuse and parent's mental illness (Kaufman & Ziegler, 1987; Wolin & Wolin 1993). These risk factors may also present themselves in the forms of several socio-economic conditions. More recently, the lens of Resiliency Theory shifted from individuals to the families as the unit of analysis to understand resiliency as a broader topic, beyond individuals (Walsh, 2003). The family as a unit

is now the new focus of resiliency concepts in a systematic view. Walsh outlined the development of family resilience from stress theory, where families are mostly vulnerable to the consequences of stress, to a more empowering view in which, "Families can emerge stronger and more resourceful in meeting future [challenges]. A crisis can be a wake-up call, heightening attention to what matters. It can become a reappraisal of new priorities…Members may discover or develop new insights and abilities" (p. 3). The outcomes manifested by the resilience of families in overcoming challenges are translated into the concept of Family Quality of Life (Singer, Paul, Wang & Ethridge, 2011), and are discussed later in this chapter.

In special education, Resiliency Theory examines and conceptualizes the experiences of families coping with the challenges of the daily needs of their children with disabilities (Patterson, 1991). Following the shifting trends in Resiliency Theory, the focus has moved from the challenges manifested in the individual child's outcomes to the experiences of the family as it copes with meeting its needs as a unit (Olsson & Hwang, 2008). The child's needs are interconnected with the rest of the family issues and overall outcome. Resiliency Theory in special education is a relatively new field. Because Resilience Theory focuses on overcoming challenges, it is connected well with research that highlights the mental and emotional stress among individuals with disabilities and their families (Patterson, 2000; Patterson & Garwick, 1994)

Several Resiliency Theory measurements have been applied in the health-related professions such as nursing, psychiatry, family therapy, and psychology. In general, researchers utilize these measures to gauge the effect and impact that significant risks such as poverty, stress, and alcoholism, have on family vulnerabilities, coping capacity, and outcomes in family adaptive systems. Examples of such measures include the Family Resilience Assessment Scale (Tucker

Sixbey, 2005), Child Depression Inventory (Kovacs, 1992), and Mental Health Inventories (Veit & Ware, 1983). These measures are adapted from family systems concepts that track child resilience in spite of socio-economic situations.

Family Quality of Life

The recent conceptualization of the family's enduring resilience is the Family Quality of Life Theory. "The idea of family quality of life (FQOL) is of central importance to understanding what is meant by family resilience" (Singer et al, 2011, p.660). According to the Beach Family Center on Disability at the University of Kansas (2006), family quality of life refers to how families' needs are met, to what extent family members enjoy their life together, and whether family members can do the things that are important to them. The Center identified five major domains of FQOL: emotional well-being, parenting, family interaction, physical/material well-being, and disability-related support.

The concept of quality of life as advocated by the Beach Center is consistent and embedded within the core principles of the IDEA law: equal opportunity, full participation, independent living, and economic self-sufficiency (Turnbull, Turnbull, Wehmeyer & Park, 2003). Family involvement and self-determination are major components of IDEA. Furthermore, there is an additional shift within the iterations of the IDEA to include more than academic outcomes, such as health and transitions to adulthood. This shift to a broader conceptualization grew out of the recognition that there is much more than academic success and access to curricula among the factors combined to define positive overall outcomes for children with disabilities.

FQOL theory is based on the individual quality of life concept, which applies more broadly to the family. In this case, a family member is defined as anyone who claims or

identifies with the group, by blood or marriage connections, or anyone who supports members in that extended group on a consistent basis (Poston et al., 2003). The two realms of individual quality of life and family quality of life affect each other.

The Beach Center on Families and Disability offers not just an expanded definition of families but also the definition of what quality of life means for the newly conceptualized unit of family (Turnbull, Turbiville, & Turnbull, 2000). This includes extended kinship relations and friends and advocates whom the nuclear family identifies as "family." Poston, Turnbull, Park, Mannan, Marquis, and Wang (2003) differentiated between the individual quality of life and the newer FQOL conception. Family quality of life, as contrasted to individual quality of life, considers all family an "aggregated" perspective (p. 319).

According to Wang and Brown (2009), the fields of disability and special education have evolved toward a family-centered approach to deliver services for children with disabilities. Furthermore, there is a growing understanding that an individual child's disability has systemic effects on the entire family network and, through collaboration with the family unit, professionals have high potential to effectively provide sustainable services for the child and family (Dunst, 1997; Parish, Pomeranz, Hemp, Rizzola, & Braddock, 2001; Turnbull, Beegle, & Stowe, 2001; Turnbull, Turnbull, Agosta, et al., 2005). This is not to say that all families of children with disabilities are the same or that they all have uniform needs. According to Wang and Brown (2009), there are needs that may be universal among families but, equally important, there are aspects of needs that are unique; and that "researchers and practitioners [must] respect the family's voice about what is important" (p.153).

There are two major scales or measures of FQOL – the Family Quality of Life Scale (FQOL) and the Family Quality of Life Survey (FQOLS). The first measure, the FQOL,

developed by the Beach Center focuses on five domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability related support. The initial study conducted by researchers at the Beach Center utilized a combination of qualitative analysis of family perception of FQOL followed by a psychometric analysis using a 5-point Likert scale (Poston et al., 2003). The second measure, FQOLS, has been used by international researchers in countries including Canada, Israel, Australia, and the United Kingdom. The FQOLS employs both qualitative and quantitative methods to evaluate nine areas of family life: health of the family, financial wellbeing, family relationships, support from other people, support from disability-related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civic involvement (Wang & Brown, 2009).

FQOL and immigrant families of children with disabilities. There is no specific study focusing on immigrant populations' Family Quality of Life. However, recent studies on FQOL with non-immigrant populations may help make some connections with existing studies done with immigrant families. Researchers shifted the lens of inquiry in understanding quality of life from the individuals with disabilities to the family (Zuna, Turnbull, & Summers, 2009). This focus highlights the notion that the needs of the individual with the disabilities are not separated or independent of the overall family's essentials for survival. Family Quality of Life considers the well-being of all family members specifically in terms of what it takes for each family member to have a good life together with his or her family (Poston, et al., 2003). The overall goal of the FQOL approach is to enhance the capacity of families to meet the special needs of their child through empowerment of the family (Bailey, et al., 1998).

While the concept of Family Quality of Life in special education studies may be relatively new, the literature on disparity and mismatch between Culturally and Linguistically

Diverse (CLD) families and Western cultural values has been well argued. McLeod (2012) contrasted the difference of values and attitude about disabilities and special education services needs between first generation, English-speaking, West Indian parents and school officials. There are a growing number of studies that explore the cultural mismatch between CLD and racial minority families and mainstream special education and other service providers (Harry 2008; Harry and Klingner, 2014; Kalyanpur and Harry, 2001; Lo, 2010; Ogata, Sheehey and Noonan, 2006; Wang and Brown 2009). Family involvement in school (or lack thereof) among immigrant populations (Tang, 2014; Lopez, Scribner, & Mahitivanichacha, 2001; Al-hassan & Gardner III, 2002) is also a growing subfield of CLD research. The connection between Family Quality of Life and immigrant families of children with disabilities remains relatively unresearched.

Chuukese as active agents of family and group empowerment. A final concept that is important in building the conceptual framework for this study is respect for the dynamic family networks of relationship and resources that engage and connect Chuukese and other islander families and communities at home and abroad. Contemporary research on Islander movement suggests a more empowering view of immigration that is culturally determined. Falgout, 2012; Hau'ofa 1994; Hofmann, 2015; Peter, 2000; Peter, 2012). In this perspective, migration of individuals and families is seen as purposeful, strategic, and family-driven.

The Intersections of Family Systems Theory, Resiliency Theory, and FQOL

What then is the intersection of Family System Theory and Resiliency Theory in the examination of Family Quality of Life? While it may be overreaching to advocate for a clear-cut picture of FQOL, several points that have been generalized about Family System and Family Resilience theories suggest what such an intersection may look like. First, FST provides an

expanded location and framework to search for and understand challenges and outcomes, a complex system that goes beyond previous traditional definitions and notions of families. Second, resilience in overcoming challenges and barriers is now understood to impact not just individuals but also, and perhaps more importantly, the family system. Three, family outcomes are predicated on the resilience of the family systems in the face of challenges. Fourth, the conceptual idea or framework for immigrant Chuukese families' quality of life in Hawai‘i can and must be understood as part of a larger, more complex web of relationships within communities. This intersection of FST and Family Resilience for Family Quality of Life for Chuukese families of children with disabilities living in Hawai‘i requires culturally-rooted research.

Summary

The theoretical framework for this study on FQOL for migrant Chuukese families of children with disabilities is a marriage of the three concepts of Family System Theory, Resiliency Theory, and Islander concepts of migration and movement. It will provide an opportunity for the Chuukese families in this study to define the boundaries and spatial parameters of their family system or network. They will inform the study of what they understand and deal with, their challenges, and factors that empower them. It will also provide historical and contemporary dynamics of their movements from their homes in Chuuk to their homes in Hawai‘i. This framework is not a static concept with fixed boundaries or an unchangeable model, but rather an ever evolving, vibrant, moving concept.

CHAPTER 3. METHODOLOGY

This chapter provides details of the case study methodology, justification for why the methodological framework was selected, and how it aligns with the purpose and theoretical basis for this study. Subsequently, this chapter presents the details of the research approach, and the techniques used for participant selection, instrumentation, data collection, analysis, and validation. This chapter concludes with a description of how the organization of this study reflects the research method, as well as result dissemination.

Qualitative Research Design

This study utilized a qualitative approach. Merriam (2002) theorizes that one of the strengths of qualitative studies is that it enables researchers to strive to "understand the meaning people have constructed about their world and experience" (p.5). Common methodologies of this approach are ethnography, case study, phenomenology, grounded theory, and critical studies. This study employs a multiple case study research methodology, wherein each family is treated and considered as a case and a unit for analysis. In a multiple case study design, the cases can be compared to identify common themes. The decision to use a qualitative approach for the study comes from several factors and goals that are compatible with the research questions.

Socially Constructed Realities

First, qualitative research supports the underlying belief that meanings are socially constructed webs of multiple realities and that there is not one set of absolute truths that determine and explain the outcomes. For the new migrant Chuukese families of Hawai‘i, who have children with disabilities and significant health care needs, this approach allows them to tell their stories without having to conform to any preexisting notions or narratives. Qualitative research is interpretative in nature. As mentioned above, it allows the participants to inform the

study about the social and cultural meanings that construct their world. It is the closest approach to the storytelling of the participants' oral traditions.

Aporous: Storytelling

Second, the Chuukese concept of aporous (storytelling), is utilized in this study to engage the participants and learn from their own stories about their experiences, beliefs, and goals for their children. The process includes both the first-hand telling of the stories and a second or third retelling of the original source of these stories. This allows researchers to confront their own biases in interpreting and presenting the data from aporous.

Researcher's Role

Third, it considers the researcher and his presence and role as a part of these families' experiences, in not just understanding, but reflecting (as also part of creating realities) on their experiences. The researcher is the primary instrument for data collection and analysis. My story and my family's story is intertwined with the participants' stories and experiences. Finally, the study is conducted in natural settings where lived realities are experienced, understood, and actively interpreted.

Qualitative Case Study

Qualitative methodologist, Robert K. Yin (1984), explains that the case study method offers the opportunity for the researcher to understand the contemporary phenomenon within the larger social context by interpretive reading and analysis of the multiple layers of meanings. Meanings are also interwoven and embedded in multiple sources of evidence. The case study research method is "an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p. 23).

Tellis (1997) explained that case studies are designed to engage multiple points of view of participants, from different sources of data, to construct an understanding of the phenomena. In this case study, I drew from multiple sources to conduct in-depth analysis of the phenomenon of living experiences for Chuukese families of children with disabilities and significant health needs living in Hawai‘i. The phenomenon is multi-layered and deals with issues of access to social services, housing and healthcare, disability, and racism. Individual units, or families, shared stories that depicted their experiences during individual semi-structured interviews. These stories reflected a diversity of the families' experiences, backgrounds, and personalities. They helped the study weave together common themes in the overall experiences of new migrant Chuukese families of children with disabilities and significant health care needs, who live in Hawai‘i.

Participants

The families were recruited using purposive sampling to meet the primary criterion: Chuukese families of children with disabilities and significant health care needs, who live in Hawai‘i. The following section will discuss the background of the participants and recruitment procedures. My role as researcher and my relationship with the participants' families is also discussed.

Sampling

Purposive sampling techniques are primarily used in qualitative research for selecting individuals or groups of individuals based on specific purposes associated with answering a research study's questions (Tashakkori & Teddlie, 2010; Teddlie & Yu, 2007). Purposive sampling was defined by Maxwell as a type of sampling in which, "particular settings, persons,

or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices" (1997, p. 87).

At the beginning of the study, I developed a set of criteria and created a list of potential families to interview. These criteria were: (a) Families must be from Chuuk, (b) Families must indicate a strong willingness to participate in the study and grant access to the researcher, (c) Families moved to Hawai‘i within the last 10 years, and (d) Families must have at least one child, born in the FSM, who has significant health needs or disability.

The first criterion required that the families must be from Chuuk State, preferably from the Mortlocks. I chose Chuukese participants from the Mortlocks Islands because I am most familiar with the language and traditional and contemporary culture and experiences of the people from this region of Chuuk State. I conducted the interviews in the Mortlockese language, my first language and the first language of the participants. The second criterion was that the families indicated a strong willingness to participate in this study. Since this study is a qualitative case study and required prolonged engagement and participation, it was necessary for the participants to be committed to the project. The third criterion was that the families moved to Hawai‘i within the last 10 years, giving them a specific immigration status that affects their access to social services.

Participant Demographics

Three families were recruited to share experiential backgrounds relevant to this research (Patton, 1990). All of the families in this study originated from the islands of Chuuk State, specifically the Mortlock Islands, and moved to Hawai‘i within the last 10 years under the terms of the Compact of Free Association (COFA) open migration policy. This means that the families have the designation of "unqualified aliens," which affects their eligibility for governmental

basic social services and financial safety net programs. In addition to having limited access to important safety net programs, they face racial discrimination and stereotyping by social service providers and the larger community. I have provided a dependable analysis on how this unique status often leads to misguided policy interpretation and decisions that affect these families.

Fourth, the families have at least one child living within the household with an identified disability or special health care need. This child with a disability was born in FSM and previously received special education services or medical pre-services in their home islands. The families, therefore, have prior experience with special education and health services on their home islands. Each case includes primary and secondary caregivers. In all three cases, the mothers are the primary caregivers for the children with disabilities. Fathers and other adult family members also participate in the daily care and activities of these children with disabilities, and were included in this study.

Caregiver roles and perspectives are central to understanding the daily challenges faced by the families. Two of the three families included mothers and fathers. The third family included only one parent (the mother) since the husband resides in the FSM. Two of the three families live in public housing and have ongoing direct experience with social service programs such as healthcare and other public assistance. All three families have experienced homelessness and living in shelters. All three families actively participate in Micronesian community events. These experiences yield valuable information regarding the challenges faced by Micronesian families in accessing appropriate supports for their families living in Hawai‘i.

Table 3: Participant Demographic Information

Demographics	Family 1 (F1)	Family 2 (F2)	Family 3 (F3)
Ancestral Home of Mother	Mortlock Islands, Chuuk State, FSM	Mortlock Islands, Chuuk State, FSM	Mortlock Islands, Chuuk State, FSM
Immigration Status, Month/Year moved to Hawai‘i	Non-Eligible Alien, June 2006	Non-Eligible Alien, April 2008	Non-Eligible Alien, January 2017
Primary Caregiver (name), First/second/third language	Mother (Rita), Mortlockese, English (intermediate)	Mother (Mar), Mortlockese, Pohnpeian (intermediate), English (proficient)	Mother (Betty), Mortlockese, Pohnpeian (proficient), English (proficient)
Secondary Caregiver, First/second/third language	Father (Phillip), Chuukese, English (basic)	Father (Ren), Chuukese, English (intermediate)	Sister (Peggy), Mortlockese, Pohnpeian (proficient), English (proficient)
Household size	9	7	9
Child (name), age, diagnosis	TJ, 19, Cerebral Palsy	Ray, 10, Mild Cerebral Palsy	Grace, 1, Hydrocephalus
Child received special education services or medical pre-services in FSM	Yes	Yes	Yes
Child eligible for social services and/or public assistance	Limited	Limited	Limited
Family actively involved in Micronesian community events	Yes	Yes	Yes

Participant Protection and Consent

A research protocol was submitted and approved by the University of Hawai‘i Institutional Review Board (IRB) (see Appendix A). Included in the IRB package were the research questions, interview protocols, and consent forms. All requirements of the IRB approval were followed.

A recruitment letter about the study was given to the families (see Appendix B). This letter, which included the consent form, was written in Mortlockese. It was also read and explained to each participant during the first meeting, prior to data collection. The initial family meeting was held at a convenient location and date where the goals and procedures of the research were explained and other families were invited to participate.

Researcher Positionality

According to Creswell and Miller (2000), the researcher should "acknowledge and describe their entering beliefs and biases early in the research process to allow readers to understand their positions, and then to bracket or suspend those researcher biases as the study proceeds" (p. 127). It is important that I, as the researcher, self-disclose my position and relationship with the topic of the study and the group selected for the research.

I have been involved with the experience of disability and the work involved in addressing issues of disabilities. I was involved with community advocacy with children with disabilities and special health care needs and their families in Chuuk State and the Federated States of Micronesia (FSM) prior to moving to Hawai‘i in 2011. For 10 years, I led the Chuuk Parent and Consumer Organization for Persons with Disabilities, and co-founded the FSM Disabled Persons Organization (FSMDPO). A native of Chuuk State, Mortlock Islands, I am an individual with significant physical disabilities and significant health care needs since the age of

15. I know the feeling of discomfort about my disability, shame when people would stare at me, and the frustration when people have not believed in my goals. I am also familiar with challenges faced by new migrant families of children with disabilities and special health care needs. I had a nephew, Jon, who had severe cerebral palsy after he was born with hydrocephalus in his brain. He lost his vision and good use of his motor skills at a very early age. To alleviate swelling in his head, doctors inserted a shunt to drain further fluid buildup in his brain, through his digestive tract.

My sister, Kutelia, was the primary caregiver and advocate for Jon. She loved and took care of him, never wanting Jon to feel that he was different from anyone else. Jon's father worked for Continental Airlines out of Guam and the family had certain tribal privileges so Kutelia and Jon traveled quite frequently throughout the islands and to Hawai‘i. Jon was smart. He had excellent memory of songs and conversations. Kutelia enrolled Jon in kindergarten in Guam. His teacher and classmates were fond of his singing. His mom once recalled getting a note from the teacher thanking Jon for teaching his class a Chuukese song. It turned out that while his classmates were singing the traditional school rhyme "Good morning, good morning, good morning, how are you?" Jon decided to sing a contemporary popular Chuukese love song made popular by the Chuukese band ReChuuk, "Nengin, nengin, en nengin ia, ka men katekat…ua mochen tongei." Jon's song, which he taught to his classmates, translates in English to, "O sweet girl, where are you from? You're so beautiful. I want to love you." Jon's mother had to apologize to the teacher after explaining to her the meaning of Jon's choice of kindergarten rhyme.

In July of 2011, my sister, Kutelia, died in Hawai‘i from breast cancer. Before she passed away she tried to train her second child, a 16-year-old girl, to take over primary

responsibility for Jon. However, Jon's care was too difficult for just one person to manage. There were too many issues with service providers, like dropping Jon's medical coverage. At one point, they mistakenly designated Jon, who was a Guam-born US citizen, as an FSM citizen, which rendered him ineligible for certain Medicaid programs. Jon got sick and he died in September of 2011. Our family had been devastated because we could not successfully advocate for him. This has had a profound effect on our family and we continue to deal with Kutelia and Jon's memories. I decided to change career goals and dedicate my efforts to learn how to advocate for underserved communities, such as the migrant and homeless populations, for health and legal access.

Researcher-Participant Relationship

The researcher must have a close relationship with migrant families to have in-depth knowledge of their situation, a trusting relationship, a sense of security, and a willingness to participate in the study (Bledsoe & Hopson, 2009). These relationship variables are necessary to enable a deep level of disclosure by the participants. Although the process of relationship building is usually a lengthy and intricate process, this study had a strict time limitation. Therefore, it was necessary to rely on the existing working relationships and well-established rapport I had previously forged with the Chuukese migrant families.

Finally, I have kinship ties with two of the families (F1 and F2). Both mothers are second cousins to my mother. F2 is from my clan and F1 is the daughter of the male chief of my clan. I knew the mother in F3 when she was a first-year college student at the College of Micronesia FSM-Chuuk Campus, when I was a teacher. These connections served to strengthen the study. I am also familiar with the three families through my current community work. As a community organizer and healthcare advocate, I have helped all of the families apply for health insurance

under the Hawai‘i Health Connector Health Insurance Marketplace under the Affordable Care Act (ACA) and have made referrals for them to other appropriate legal and social services.

Data Collection

Data for this study were collected through individual semi-structured interviews, focus groups, and document analysis.

Aporous: Relationship-Building

The interviews and focus group were conducted through an indigenous Chuukese aporous (storytelling) format, akin to the Tongan talanoa (Vaioleti, 2006) and Marshallese bwebwenato (Nimmer, 2017). This process of aporous included meeting four or five times in various locations with each of the mothers before the actual semi-structured interview took place. These earlier meetings included aporous about island life, participating in Catholic funeral novenas, watching movies, and spending Sunday afternoon eating together at the first family's home. The husband, who works for a fish auctioning company, would bring home lobsters, fish, and other seafood from the auction, to share with all of the families. This helped the families feel more comfortable with me, as part of their regular activities. Also, I met the third family several times at the shelter as part of my professional work. Oftentimes, after work, I would spend hours talking with the mother, the children, and the grandparents. Most of the time, conversations were about sharing stories and news from the islands. In the process of aporous, we discovered a clan-kinship connection with the grandfather.

Semi-Structured Interviews

The primary data collection was done through individual semi-structured interviews. The three mothers in each family were the primary sources of information because they were the main caretakers and decision-makers for the children with special health needs and disabilities. A set of open-ended and semi-structured questions were developed for the interviews with the mothers in this study. Other family members were interviewed as secondary and tertiary sources of information. Their perspectives were also crucial in supplementing and triangulating the data gathered through the primary semi-structured interviews. A similar set of interview questions was created for these secondary caregivers.

I utilized a system of translation and transcription that I developed for my earlier studies, which also were conducted in Mortlockese. Data collected through semi-structured interviews and focus groups were stored in an electronic format so I could simultaneously listen to the session on a headset and dictate the English translation into a Word document. I used Kurzweil 300 voice recognition software.

I spent hours listening to the interviews in the Mortlockese language, paying close attention to individual words, trying to capture the emotion behind the words and the non-verbal cues. This close attention to culturally-bound nuances is particularly important in oral languages like Mortlockese, to ensure that relevant data were not lost in the exhaustive coding process. Chunks of important meanings such as single words, phrases, or clauses were methodically analyzed and coded accordingly.

I invited two external reviewers to examine the transcription. It was important to include language translation accuracy checks so that the data were not compromised in translation and interpretation. Two Mortlockese trained and certified language translators and interpreters

performed this task. The transcription and recorded Mortlockese translations were shared with the participants as a member checking mechanism to ensure accuracy of the data transcription and to provide further input.

Research Setting

It was important that these Chuukese families felt comfortable in the interview settings and when sharing their stories. The cultural appropriateness of the questions and the engagement was ensured. This began with me, Joakim Peter, and being upfront about what I am doing, why I was doing it, and how they could help me. I shared with them my story, and doing so in a personal way was important. I talked in the first-person, sharing with them about my family's experience here in Hawai‘i, which made my own family story relevant to their experience. All semi-structured interviews were conducted in Mortlockese.

The one-on-one semi-structured interviews were broken down in two individual sessions. While the meetings lasted several hours, the recorded semi-structured interview portion ranged in length from 30 to 60 minutes. The semi-structured interviews took place in the family's homes and shelter area. The families were familiar and comfortable with being interviewed in their home environment. All one-on-one and focus group sessions began with prayers, sharing of relevant stories, and ended with providing and sharing food. It is part of our Chuukese culture to bring food to our meetings no matter the size of the group or the level of interaction. It shows respect for the people we meet and the occasion of the meeting.

The first session covered the first and second research sub-questions about the participants' memories and connections to their home islands and places, the push factors for moving to Hawai‘i, and the issues and barriers they faced in Hawai‘i. It also addressed the

perceived needs of their children with disabilities, or special health care needs, and how this related to the overall conception of the family's needs.

The second session addressed the third research sub-question and other topics that were brought up during previous sessions and conversations. The focus was on the solutions that families utilized when encountering or identifying challenges. The third research sub-question dealt specifically with the families' perceptions and engagement of the various programs and services for their child with disabilities or special health care needs.

As mentioned above, the semi-structured interview questions were designed to keep the participants engaged and feeling comfortable enough to open up during the interview sessions. The families told their stories. Their narratives were woven with my own shared stories.

Focus Groups

Focus groups are often used in research to study different social groups and in cross-cultural and development research. Anthropologist Pranee Liamputtong described focus groups as an instrument that can create knowledge for social transformation (2011). He argued that, "focus groups are ideal for many people from ethnic minority groups" (p.6) in cross-cultural contexts because the methodology reflects the collectivist nature of social groups which empowers participants who might otherwise shy away from articulating their thoughts. Therefore, semi-structured group interviews provide a means for harnessing the collective power of those who may be marginalized by society.

An essential trait of Chuukese family culture is the need for group-consensus in disclosure by identifying with familiar persons with similar experiences (Hezel, 1992; Iding et al, 2007; Ratliffe, 2010; Innocenta Sound-Kikku, Personal Communication, July 10, 2015). Thus, semi-structured interviews were used in focus groups as a means for providing a comfortable and

familiar context for the participants to share their stories and common experiences. A follow-up focus group discussion was conducted with a group of the same participants after the transcripts were analyzed. This served the purpose of prompting further discussion on themes that needed elaboration. The focus group provided an opportunity for the participant families to engage with each other and helped to empower them to share their stories.

The topics of the focus group discussions came from themes from individual interviews. The purpose was to confirm data across cases and check for accuracy. To facilitate the focus group session, I shared my family's story about my late sister Kutelia and my nephew Jon. The focus group lasted one hour. The setting was at a third location, my home. Like the one-on-one semi-structured interviews, the format included prayers, introduction of participants, and partaking in a small potluck.

Document Review

Document review was used to gather facts and background information relevant to understanding Chuukese families' perspectives. Dvora Yanow (2007) contended that,

> Document reading can also be part of an observational study or an interview-based project. Documents can provide background information prior to designing the research project, for example prior to conducting interviews. They may corroborate observational and interview data, or they may refute them, in which case the researcher is 'armed' with evidence that can be used to clarify, or perhaps, to challenge what is being told, a role that the observational data may also play. (p. 411)

Therefore, I conducted a document analysis of laws, regulations, and policies relevant to the Chuukese migrant families in Hawai'i, in order to formulate a complementary analysis of the

issues facing families of children with special needs, to situate their stories within the larger narrative of the FQOL framework.

Analytic Memos

In qualitative studies, the researchers are the primary source of information or data collection (Creswell, 2013). That means that the researcher and his or her reflection on any aspects of the data collection process is also part of the primary source. I primarily used an audio journal to record my personal observations during each step of the research. The journal was stored on a hard drive and properly organized and kept as part of the primary source for the audit trail. This provided an additional perspective and also a means to triangulate the data.

Data Analysis

Miles and Huberman (1994) suggested that qualitative data analysis consists of three key stages: data reduction, data display, and conclusion drawing/verification. The data can be reduced into units of meaning, or data chunks, using three procedures: open, axial, or selective coding. Coding is the process of organizing raw data to draw out the thematic and conceptual categories. As Miles and Huberman noted, "Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes are usually attached to 'chunks' of varying size – words, phrases, sentences or whole paragraphs" (1994, p. 56).

The coding process of qualitative data is encompassing of not just the recorded data or interview, but must also include notes from observations that may support subsequent data analysis (Miles & Huberman, 1994). These codes can then be displayed or organized to allow for the drawing of conclusions.

Coding

Following the reliability and member checks, I coded and analyzed information from the final transcription. This provided themes and subthemes that fed into the participant focus group. These themes became further refined after the focus group. I reviewed the data against the research questions to determine how the data informed the study.

Data reduction refers to the process by which I organized and reduced the quantity of qualitative data collected, such as interview transcripts, field notes, and personal observations. For example, I created a coding table for the individual interviews and the focus group. To draw conclusions from large amounts of data, Miles and Huberman (1994) suggested that a good *display of data*, in the form of tables, charts, networks, and other graphical formats is essential. This was done through a continual process that allowed me to recognize patterns of information and develop an effective analysis of the data. These initial conclusions were then verified by examining the validity through reference to my existing field notes or further data collection.

During *open coding*, I reviewed the data through close and careful reading to ensure that all statements relating to the research question were identified, and each was assigned a code, or category. I assigned as many codes as I found necessary to identify the thematic patterns in the data texts. These codes were then noted, and each relevant statement was organized under its appropriate code.

Then, using the categories developed during open coding, I reread the qualitative data, and searched for statements that fit into any of the categories. Further codes or parallel categories were also developed in this stage when certain information could fit in multiple categories. Once these first two stages of coding were complete, I analyzed and searched for patterns and explanations in the codes.

Finally, through *selective coding,* I read through the raw data again for cases that illustrated the analysis, or explained the concepts. Here, I looked for data that were contradictory, as well as confirmatory. I was careful to avoid confirmation bias, or the tendency to seek out and report data that supported my own ideas and biases about the key findings of the study. Coded data were then organized, whereby the data units (statements, sentences, etc.) were clustered into common themes. Similar units were grouped together into first-order themes and separated from units with different meaning. The same process was then repeated with the first-order themes, which were grouped together into second-order themes.

Triangulation

Qualitative researchers generally use triangulation to ensure that analysis is robust, all-encompassing, and well-developed. A single method of analysis is inadequate to explain an information-rich phenomenon such as the experiences of these three families. I combined the analysis with findings from multiple data sources to demonstrate trustworthiness.

Denzin (1978) and Patton (1999) identified four types of triangulation. The first type, methods triangulation, involves examining the consistency of findings generated by different data collection methods. The data collected through the semi-structured interviews were corroborated with other means of data collection such as document sources and personal observation. The second type is triangulation of sources. This approach was used to examine the consistency of different data sources from within the same method. For example, data were collected through semi-structured interviews from the mothers and fathers in the same family, often providing complementary views on the same data. The third type, analyst triangulation, entails using several observers and analysts to evaluate perceptions or highlight an area that may have been overlooked in the interpretive analysis. The goal is to understand multiple ways of

seeing the data. I used two interpreters to double check the translations. In several instances, they had different interpretations of the participants' meaning, use of terms, and nonverbal cues in their answers. The fourth type, theory/perspective triangulation, employs multiple theoretical perspectives to examine and interpret the data. The theoretical perspectives in this study are related because they focus on the structures, resiliency, and quality of lives in families of children with special needs. Given this connection in focus, it was not unexpected to find coded information applicable to two or more of these theoretical perspectives. It was also illuminating when the indigenous Chuukese cross-thematic concepts were utilized to explain cultural context of family network and resiliency and quality outcome.

Trustworthiness

Lincoln and Guba (1985) first established four criteria for ensuring trustworthiness of qualitative data: credibility, dependability, conformability, and transferability. Credibility entails ensuring the "truth" value of the data, and how strongly the data represent the study. There were several ways to do this in this qualitative case study. First, I made sure that those participating in the research were identified and described accurately in ways that satisfied the purpose of the study. I ensured sufficient and prolonged engagement with the participants to get as much information needed to satisfy the research questions. This process is also referred to as data saturation, the point where useful data are sufficiently collected. Other means to ensure credibility include doing peer debriefing with an independent third-party researcher and member-checking with the participants. As indicated, I invited two researchers who were also language interpreters to look over the data to ensure the accuracy and reliability of the information. Each participant was given an opportunity to review the data collected as well as the results in their

story. One out of the three mothers interviewed for the project made significant changes to the transcript of her story, which proved to be very useful in the analysis.

The dependability of the data was ensured throughout this process involving several modes of triangulation. Further assurance of dependability was provided through other means such as review of the data collection process and other procedures, analysis, findings, and conclusions in the study. I have established an audit trail to allow for an external review and critique of the findings. This consists of journal-recording and self-memos.

Confirmability supports the objectivity of the research findings and the level which the findings reflects evidence in the data. This also entails disclosure or examination of research bias. Transferability for this study can be assumed for similar populations.

This qualitative study utilized aporous (storytelling) to provide what Merriam (2002) referred to as thick descriptions and ethnographic notes for the data collection and other steps in developing analysis conclusions.

Indigenous Narrative Strategy. This study has attempted to honor the cultural background of the participants by employing an indigenous narrative strategy, aporous (storytelling), to understand and discuss space and movement. Using indigenous narrative is a strategy to highlight the participants' cultural identities in the processes of data collection, analysis, and reporting in research. I strongly believe in featuring a voice of indigenous people, especially in studies featuring their experiences. Conducting research with indigenous people necessitates a deep understanding of the myriad of ways in which power dynamics, colonization, and knowledge appropriation intersect as well as the recognition that "the pursuit of knowledge is deeply embedded in the multiple layers of imperial and colonial practices" (Smith, 1999, p.2).

This strategy is useful in the pursuit of the layers of meanings that are embodied in significant narrative.

Indigenous narrative strategy was essential to this study because it illuminated issues of historical and contemporary forces that motivated Chuukese islanders' movement from their home islands to Hawai‘i. Consideration was afforded to the rich narrative traditions of the people, not just of the spoken language, but songs, chants, symbols, values, beliefs, perspectives, and traditions, to name a few. This process included collecting and representing the rich descriptions in the stories told by the participants.

Summary

Participants were selected through purposive sampling. Case study data were collected through individual semi-structured interviews with safeguards, including independent reviews and audits of procedures, notes, and self-memos, member checking, and triangulation and cross referencing of data, to ensure reliability and validity of data collection. Following the data collection, I identified and categorized outcomes and practices within a Family System Theory, Family Resilience Theory and, Family Quality of Life theoretical framework to propose recommendations for change.

CHAPTER 4: STORIES OF FAMILIES' TRAVELS

This chapter tells the stories of each family's experience with disability and their travels from their home islands to Hawai‘i. These stories are woven together from individual interviews, focus group discussions, my observations, and from documents provided by the families and other sources. To appropriately capture the voices of participants, their direct words within a paragraph are in standard font, while their longer quotations are presented in italics to delineate their words from mine, the researcher. The stories tell about the experiences of each family at home, in Hawai‘i, and other places outside their home islands, and about their experiences dealing with their children's special needs and disabilities. These experiences are about past events, people passed on and places departed, told through great emotions of tears and laughter; they are also about fresh experiences that are currently encountered and narrated with intense raw emotion.

TJ's Story

TJ was born on March 19, 1997, in Pohnpei, FSM. His parents, Rita and Phillip, decided it would be safer for TJ to be born either in Pohnpei or Guam, rather than in the Chuuk Hospital on their home island of Weno. Rita was not confident in the quality of Chuukese medical services given the risk of complications associated with her first childbirth. Rita had Pohnpei relatives who came from the Mortlocks region of Chuuk. They maintained strong kinship connections with eterenges (extended family) and ainang (clans) through visits back and forth. Phillip, too, had an ancestral lineage originating from the Mortlocks, although he himself was born and raised on Weno.

Right after his birth, the medical staff noticed that TJ was in distress. The doctors informed the parents that TJ was suffering from a debilitating condition (later identified as

quadriplegia due to Spastic Cerebral Palsy) that would affect TJ's physical growth, speech, and mobility.

"The baby would cry so much and looked like he was having pain when urinating. They had to operate on him to enable him to pass urine," (Rita).

The prognosis proved to be correct: TJ's development was slow and challenging. Phillip noticed that "TJ would just lie motionless for long period of time." As he grew older they observed contractures and stiffness in his arms and legs that negatively impacted his movement and coordination. TJ had difficulty speaking. He was unable to sit or turn when lying down. His rigidity made it difficult for him to feed himself. He had to be fed slowly to avoid choking. In spite of his challenges, TJ remained vibrant and happy. He loved being with his family, especially his grandfathers. He loved kkel (songs and singing) and tutulap (stories and storytelling). Although his speech was difficult to understand, it was evident to Rita and others that he was intelligent.

Four months after TJ's birth, the family returned to Weno from Pohnpei. They moved in with Phillip's family. At the age of three, TJ entered the Special Education preschool program in his village. Rita was unsatisfied with the services and outcome of the preschool program because TJ's schooling was inconsistent. Sometimes the special education bus would not come to pick him up. After preschool graduation, he received sporadic home visits from the Related Service Assistants (RSA) staff from the Department of Special Education. The support was not dependable. The home visitation team often canceled visits and services due to problems with transportation. Rita did not understand the IEP process, so she did not participate in team building, planning, or implementing her son's formal education.

"After we returned to Chuuk [from Pohnpei] in August or September we went to [the Mortlocks]. We stayed there about a year…we returned to Chuuk (Weno), because now we realized that he was sick. He had a hard time urinating, and when he did it had blood in it because he had a stone, kidney problems." (Rita)

The family resided in Chuuk for eight years after TJ's birth. Rita and Phillip had two more sons. They lived intermittently between Weno and Rita's home island in the Mortlocks until TJ's health needs became too severe. TJ needed surgery to remove kidney stones when he was 9 years old. His parents decided that the risks were too high for him to undergo the surgery at the Chuuk State Hospital. Rita and Phillip expressed frustration over the treatment TJ received at the Chuuk Hospital after he began passing bloody urine while they were in the Mortlocks.

"When we returned to Weno…we asked them to check what was wrong with him. They did not know. We went in and come out but they did not tell us what went wrong." (Rita)

TJ's doctor at the Chuuk State Hospital referred the family to a visiting medical group from Healers Hospital for Children. TJ was experiencing severe pain in his joints as his muscle tone had become increasingly rigid.

"At that time he was seen by a doctor from here (Hawai'i). He came (to Chuuk). They were going to process his paperwork to come up to Healers. We waited, and waited but it never worked out." (Phillip)

For reasons unknown to TJ's parents, the application for Healers help was not approved. The family returned to the Mortlocks for three more years but TJ's health became critical with kidney stones.

"Out there, it got worse in '03, we returned to Chuuk '04, '05, then when Jenny told us to go see her in Saipan, we took him to get medical treatment in Saipan. We arrived in October, then on December 3rd, they did surgery on him and took out his "stone." That time he was relieved." (Rita)

In October 2005, the family moved to Saipan to reside with one of Rita's older sisters, Jenny. Rita was in her eighth month of pregnancy with their fourth child at the time of the move. TJ had the surgery to remove the kidney stones and subsequently recovered quickly.

Jenny and Rita enrolled TJ in the neighborhood elementary school in Saipan. For the first time, Rita became involved in TJ's education: attending school events, parent-teacher conferences, and IEP meetings. Jenny served as a family advocate and interpreter at the meetings. Rita's knowledge of special education processes, including possibilities and expectations for parent involvement, increased.

Rita was visibly upset as she recalled an incident that TJ experienced at school. TJ had soiled his pants. His Education Assistants (EAs) were arguing with each other over who was going to change him:

"One of them finally changed him, but she was also talking to him, while she changed him. She did not know my son understands, but he cannot say anything. She was telling him that his feces smelled and told him that Chuukese are crazy … and my son was just quiet, like she changed him but she did not really want to. They tried to open up his legs, but he didn't want to. It was like the woman who changed him and also talked to him. When they tried to change him, he locked his legs. He started to cry...he cried, cried and cried and that's what they were having problem so they called me. The entire time I was talking to them, he was just crying. I told them to put me on speaker phone and he just said to "come quick." (Rita)

TJ repeated the aide's racist comment to his aunt and mother. Jenny complained to the school principal who subsequently apologized to Rita. Reportedly, the aide was disciplined, but the disgusting memory lingered.

Rita reconnected with the Healers physicians while in Saipan. The doctors referred TJ to Honolulu for surgery on TJ's hips; this time his case was approved. Rita and TJ arrived in Honolulu on May 21, 2006, and TJ was admitted to Healers Hospital for the surgery. Rita stayed at the hospital with TJ for several weeks. With assistance from medical referral officers from Saipan, Rita and TJ moved to the Ronald McDonald House in Mānoa so TJ could recover. They returned to Saipan on the 4th of July with instructions to return for a follow-up visit the next year.

The family moved to Guam in 2007 for Phillip to find work. He secured employment with a cleaning company, allowing the family to rent an apartment and to send the children to school. TJ attended a middle school in Dededo as a sixth grader. Rita again met with Healers physicians when they visited Guam in March 2008. The physicians referred TJ to Honolulu again for surgery.

Rita needed someone to help take care of the other children so she could travel with TJ. One of Phillip's female cousins moved from Chuuk to Guam to help out, and in June of 2008, Rita and TJ returned to Hawai‘i for a second surgery. TJ was operated on and prescribed medications to alleviate spasms and contractures in his arms and legs.

"After the surgery, his doctors told me to bring him because that thing has been staying in him too long. That's when I came up here. They told me to stay because he would need to have an appointment every 3 to 6 months… I told them that I could not stay here because I did not have any family here. They said that there are "shelters" and I ask, "What is a shelter?"

Because I did not understand anything about those place that they were telling me about. And I said I do not know anything about here." (Rita)

Rita was deeply concerned about staying in Hawai‘i. She knew that her family could not afford to fly back and forth from Honolulu to Guam, and she was concerned about leaving her three other sons and husband unattended in Guam. Although her husband had recruited a female relative to help care for the children while he worked, it was not a satisfactory long-term arrangement. In addition, TJ was afraid of flying which further convinced Rita and her husband to consider permanent relocation to Hawai‘i.

Upon their arrival in Hawai‘i, Rita and TJ moved in with Rita's cousin, Cindy, and her family. This created an overcrowded situation that drew warning of eviction from Cindy's landlord. Two months later, Rita and TJ moved in with Rita's uncle James in public housing in Kalihi. Phillip and their other three boys, who had just arrived from Guam, soon joined them. James, too, was warned by housing authorities that his home was overcrowded and in violation of code.

Rita and Phillip decided to move their family to a homeless shelter, even though they had heard "horror stories" of shelter conditions. They had considered moving back to Guam, but TJ's medical condition weighed against it. On April 18, 2009, the family moved into a shelter, where they resided until August 12, 2009. Rita described the five months that they lived in the shelter as difficult for everyone in the family, especially TJ who was recovering from a recent surgery. TJ slept fitfully, "he would cry and cry for long time…sometimes until the morning. I would sit up all night when he cried," recalled Rita. The shelter was hot, crowded and noisy, with little privacy. During the day, the family walked to Uncle James' apartment at the nearby public housing for rest, showers, food, and family time.

Rita enrolled TJ at a middle school, where he repeated 6th grade. His immediate younger brother, James, was enrolled at a nearby elementary school. During the day, the two youngest boys who were not yet school-aged, stayed with relatives at nearby public housing while Rita attended to daily routines such as delivering the older boys to school and taking TJ to medical appointments. Phillip secured employment at a restaurant in Waikiki, working from early afternoons until 2:00 a.m. He usually arrived home to the shelter at 3:00 a.m., unless he missed the last bus, in which case he arrived at 5:00 a.m. After a few hours' sleep, Phillip watched over his youngest boys at public housing until it was time for him to go to work.

The social worker at the shelter assisted Rita and her husband to secure appropriate social services, including public housing and health insurance. Rita herself needed health care support as she was hospitalized twice and needed surgery for different illnesses during the family's five-month stay at the shelter.

On August 11, 2012, the family moved to a transitional studio apartment on Punchbowl. The transitional studio shelter had a 2-year term limit, but the family received a third-year extension. Rita was grateful to the transition shelter for extending their stay.

The family's life in Honolulu continued to be an ongoing struggle. The studio apartment was crowded with all six family members and a female relative who was brought to Hawai‘i to help with the children. The female relative who had been brought from Chuuk to help with childcare soon elected to move out on her own. Phillip secured a second full-time job, this time at a bakery near the airport. Phillip worked the day shift at the bakery, returned home for a few hours to eat, shower and rest, and then worked a full shift until 2 a.m. at the restaurant in Waikiki.

When TJ moved to ninth grade at the neighborhood high school it became more difficult for Rita to respond to the increasing demands. Rita described the negative perception, attitudes, and behavior by school officials whom she encountered. One telling example occurred the day she arrived late for TJ's IEP meeting. Rita did not have bus fare so she walked 1.5 miles from their studio apartment on Punchbowl to pick up her two sons from their school. She then dropped them off with relatives at Nu'uanu housing, and then walked another mile to TJ's school for the meeting. Upon arrival she was informed that the meeting was nearly over. They handed her a printed copy of the IEP, which had been completed in her absence, and asked for her signature of approval. Rita said she did not understand the form and requested an interpreter. Several team members expressed their frustration, accusing Rita of not caring for her child. This drew tears and an angry response from Rita, who left the meeting refusing to sign the IEP document.

Rita also recalled her negative experience with the social worker when she confided in the counselor that she needed assistance in retrieving her children from school. Rita explained that with her three kids in two different schools, it was difficult to pick them up.

"I have three other sons and I have to go over to pick them up then no one is there to go and get my son [TJ] from McKinley. My counselor was very rude to me and she told me to better take care of my own sons." (Rita)

On several occasions interpreters were not available during school meetings which made communication difficult. Rita expressed dissatisfaction with the quality of physical care provided to TJ while he was at school. At one of his IEP meetings, the team asked her to identify areas of concern. Rita addressed issues of mistreatment and mishandling as related to medications, seating and positioning, and feeding. Specifically, she noted that TJ's medications

were being administered haphazardly rather than according to schedule, which could trigger seizures and spasticity. Further, he was permitted to twist his body to such extremes that he was at risk either to fall from his wheelchair and/or twist his wheelchair supports out of alignment.

"I said you know there is a part of his wheelchair that is supposed to keep his legs from clamping together. Many times when he comes home that piece is falling off the chair because my son has very strong and stiff legs so if he is not sitting properly he would clamp these links together very tightly and that on his wheelchair would almost fall off. They are not paying attention to him properly. They don't know how to help him. So then he could get hurt from their carelessness." (Rita)

On one occasion, Rita was called to the school to lift TJ back into his wheelchair because the aides feared hurting him should they attempt to do it themselves. Rita also expressed concern that TJ was being rushed through his feeding, depriving him of sufficient time to chew, swallow, digest and enjoy his food. One day TJ had to be taken to the emergency room because of a feeding emergency.

"I told them that my son cannot eat chips…because he will choke on it. TJ told me that he ate chips. When they had snack, they put chips in his mouth and he choked on it. He, himself, told me this. He was sent to the emergency, but we were not home. My husband and I went to visit my cousin. The teachers tried to call us from after 10 o'clock [until] 1 o'clock when we finally received their message. We went straight from there to the hospital. TJ was breathing like he was going to die." (Rita)

On August 11, 2012 — after overstaying the 2-year term limit at the transitional shelter— the family returned to the homeless shelter, where they remained an additional six months, until given the opportunity to move into a 3-bedroom apartment in Wai‘anae. The family moved to

Wai‘anae on March 1, 2013, appreciating the spaciousness of their new apartment. The three younger boys slept in one bedroom; TJ had a bedroom of his own.

Rita attempted to register TJ at Wai‘anae High School but was informed that the school was unable to accommodate his related services requirements, such as keeping his medicines properly refrigerated. The school officials advised Rita to maintain TJ’s enrollment at McKinley High School in Honolulu, even though it was 30 miles away. They did not offer to provide transportation. Rita was left with the understanding that she and her husband would have to be responsible to transport TJ themselves.

Rita and Phillip decided that if TJ would have to commute to the city, then the entire family should travel together. Phillip quit his employment at the restaurant in Waikiki, but kept his job at the bakery. The family awakened daily at 3:00 am to prepare to take the first bus from Wai‘anae into the city. After an hour’s commute, Phillip dropped off the younger children at Ka‘iulani Elementary School and then caught a second bus to the bakery. Rita accompanied TJ to McKinley High School.

“I would drop them off at school and catch another bus out to the bakery. So I would bring the kids to the school by the public housing then catch another bus to work. So when they finish school someone [his relatives] at the housing would look after them and wait for me until I get off work. So after work I come to pick them up and we would catch the bus back to Wai‘anae. We would reach home around 8 p.m., or after. We would catch the bus around five during heavy traffic so it would take hours getting stuck in traffic. We would all fall asleep on the bus. Just get on the bus and sleep. Same thing in the morning, catch the bus and fall asleep.” (Phillip)

After more than a month of this exhausting routine, Rita stopped taking TJ to McKinley High School. Rita determined that it would be better for TJ’s health to keep him at home. School

authorities never contacted Rita and Phillip regarding TJ's absence. TJ missed school for the remainder of the Spring. Phillip said that it was a difficult decision but concurred with Rita that TJ was too weak and tired from the long trips.

"Then we just had to tell his teacher that it was too difficult for us to bring him to school every morning from Wai'anae to McKinley. What could we do?" (Phillip)

Summer 2013 was to bring the family much needed relief and a turning point in the family's welfare. The Hawai'i Public Housing Agency (HPHA) phoned with exciting news: Rita and Phillip were invited to relocate to a newly renovated 5-bedroom unit in the Mauka Housing Complex. After more than four years of dislocations in and out of shelters and transitional housing, Rita, Phillip and the children moved into their new home on June 17, 2013 where they reside to this day. The rent on the unit was based upon a percentage of the family's income, allowing the family to save money and purchase a car.

Rita and Phillip are delighted with their new accommodations, often holding family events and hosting visitors in their home. TJ now has his own room on the first floor with his own accessible bathroom. His siblings share two rooms, inviting cousins and friends to stay overnight. The family subscribes to the Internet, giving them access to friends and family in Saipan, Guam and even the small island in Chuuk where Rita's parents still reside. TJ receives video DVD's from the islands. He watches his grandfather on video and communicates via Skype web-based conferencing. Because of funding from the FSM national government, many islands in the Mortlocks are accessible via satellite to the Internet. Although the signal is moderate-to-poor in quality, it is sufficient for TJ and his family to maintain voice contact with the grandparents, which is especially important to TJ, who often expresses how much he misses his grandfather.

Phillip quit his job at the bakery, and secured employment with Rita's cousin at Fresh Island Fish, a seafood wholesale distributor. He was offered a higher salary than at the bakery and was promoted six months later. Occasionally, he brings home fish and lobsters to treat family and friends. Although TJ has undergone several more hospitalizations and surgeries, Rita reports that she is better able to handle the stress given her family's improved circumstances.

Rita now has a positive rapport with the teachers and staff at Farrington High School which is TJ's new school. She volunteers at the school. There are still some disagreements, but they have been resolved successfully in the IEP meetings.

Last year, TJ was injured on his way home on the special education school bus. The driver had not properly secured TJ's wheelchair, which fell over in the van with TJ strapped in. Rita called an ambulance, secured a doctor's report, and filed a complaint with the school for negligence. She was able to get support from a nonprofit legal organization associated with one of the community clinics in Kalihi.

On other occasions, the teachers' aids neglected to meet TJ at the bus when he was dropped off in the school parking lot. TJ sat in the lot waiting for their late arrival. These concerns, too, were brought up and handled through the IEP meeting.

Recently, TJ's grandfather came to visit the family. He had medical concerns, which required surgery. Rita was able to raise sufficient money from among her siblings and other family members to bring her father to Hawai‘i for the surgery. This visit made everyone happy, but no one was happier than TJ who spent most of his summer enjoying his grandfather's singing and tutulap (stories).

Baby Ray's Story

Although Baby Ray's mother, Mar, was born and raised on the island of Weno, she and her family maintained a strong identification with their Mortlockese heritage—including its language and culture which were different from the lagoon island of Weno. Mar's parents moved to Weno in the 1970s because of her father's employment with the telephone company. Mar was born shortly after their arrival.

The family traveled back and forth to their island in the Mortlocks, maintaining close relations with their extended family. Mar remembers swimming and fishing in the lagoon, and playing with her kinship relatives. These trips were to become indelible memories of Mar's childhood and identity. To this day, Mar's accent is unmistakably that of Mortlockese. She also fluently speaks the "Lagoon Weno" Chuukese, which highlights her connection to the village on Weno where she grew up. In short, Mar is bicultural and bilingual.

Mar attended elementary and high school on Weno. She subsequently attended the College of Micronesia–FSM, in Pohnpei, where she graduated with an associate degree in Liberal Arts. Mar then returned to Weno where she became an elementary school teacher and married Ren, a local man from her village. Mar and her husband had their first child, Kate, in 2001 at the Chuuk State Hospital. Their son Ray was born five years later, on February 22, 2006. Mar did not have any cause for concern throughout her pregnancy with Ray. The pregnancy came to full term. The delivery process was normal. Although Ray weighed 10 pounds, which was large, his weight was within normal limits.

"There wasn't anything that was different between my pregnancy with the two children, except for some thoughts that I was going to have twins. I did not suspect anything because I

believe I was very careful in doing my follow-ups, taking my medications from the doctors." (Mar)

"When I gave birth to Ray there was no health issues I was aware of right away. I did not think he had any disabilities. I saw him when I gave birth and he was OK. The mid-wife who helped with the birthing was very helpful and guided me through the process." (Mar)

Mar noticed, however, that the attending nurses and doctors appeared to be concerned upon examining her baby. Ray was placed in an incubator and given injections into his legs. Mar was never told what this treatment was for, nor was she apprised of any prognosis.

"The next day the doctors and nurses came and told me that they needed to give him vaccine shots because they claimed he had some infections. That's when I suspected that something was not normal because he was getting these shots every day. They also put him in a glass container like the incubators where they put the premature babies. So, they would continue the shots every 11 o'clock in the morning and 11 o'clock in the evening." (Mar)

Mar was told that the baby had an infection and that his head, which appeared to be enlarged, would reduce in size once his infection abated. Confused and disturbed by the doctors' communication, Mar and her baby were soon discharged from the hospital. She kept her appointments at the hospital without fail, always probing the nurses and doctors for more information on her baby's condition. Meanwhile, Ray's health deteriorated. Mar observed that the baby was losing weight and his physical movements seemed atypical. His neck was not fully supporting his head, which hung loosely. His arms and legs appeared to be weak, too. Mar's concerns only grew as the months passed.

"After months of appointments, I realized that Ray was having some difficulty in his development. I would take him to the hospital to talk to the nurses and some of the female

doctors about Ray's condition…After a few days I realized that Ray was having difficulties… They did not tell me exactly what was wrong with my baby, but I knew that something was not right with him. We would take the baby to the clinic for his regular shots. He was not moving normally like other babies and he started losing weight. He was born big and looked healthy but then he started to lose weight and became very thin." (Mar)

After eight months, Mar's parents and related elders sought help from traditional healers, but there were no signs of improvement. Ray's general health continued to worsen. Finally, during one of their regular visits to the Chuuk State hospital, a Healers team of visiting doctors examined baby Ray. Ray's father recalled the concern expressed by the doctors upon examining the baby. They explained that Ray's vertebrae were not developed properly in his neck area.

"[They] examined Ray and we told him about his problems and he asked us to seek medical referral to send Ray to the hospital in Hawai'i." (Mar)

Ray would require a surgical fusion to stabilize his neck. Such surgery could not be performed in Chuuk. Upon advice from the Healers team, Ray needed the surgery soon. The family saw no other option than to travel to Hawai'i. Mar confronted her baby's doctor after learning about his prognosis by the Healers doctors.

"So I took my baby back and asked him about my child's condition. He told me that my child has a debilitating condition caused by his spinal cord. I asked why he never told me about this before and he said that he informed my father-in-law about it. I told him that he should've informed my husband and me about the child's condition… That's when I decided that we were going to find out how to provide support for our son. We started making plans to bring Ray to Hawai'i." (Mar)

Since the referral had not come from the Chuuk Department of Health, the family had to pay its own travel expenses. The family raised the funds for Mar, Ren, Baby Ray and Kate (who was then 7) to embark on their trip to Hawai‘i. Ren recalled, “We decided to come to Hawaii on our own. No medical referral from the hospital.”

Upon arriving in Hawai‘i in April 2008, the family moved in with one of Ren’s uncles living in a public housing complex in Honolulu. Soon thereafter, a family member introduced them to the public health clinic in Kalihi. Mar described the clinic workers as very helpful in assisting her to apply for public assistance, including healthcare insurance and public housing. A pediatrician referred Baby Ray to Healers for a more complete diagnosis. Because Baby Ray was only one-year-old, it was decided that any surgery to his spinal column should be postponed for two years. In the interim, he was to be monitored closely through monthly visits to Healers. Mar and Ren expressed relief finally to receive competent medical advice.

The family’s housing situation was difficult to resolve. Although Ren almost immediately upon arrival secured employment at the airport, the family could not afford to rent a place of their own. The housing situation was exacerbated by the fact that Baby Ray required around the clock care. He cried persistently, demanding that Mar alone handle him. On occasions when Baby Ray napped, other family members attended to him, so that Mar herself could get much needed rest or attend to other family responsibilities.

“With Ray’s condition it was very difficult to live with other people because he would cry all night. He was suffering most of the time. No one else knew how to handle him besides me. I could not sleep and suffered lack of sleep a lot. I would cry and pray.” (Mar)

Mar began to feel that her baby and her family presented an undue burden on her husband’s relatives. Mar and Ren decided to relocate their family to the home of one of Ren’s

aunts at another public housing facility. This solution was short-lived. The public housing officials sent Ren's aunt a notice of non-compliance, which had been promulgated by the neighbors complaining that Baby Ray's cries created a disturbance. The family would have to move again.

A social worker from the clinic in Kalihi referred Mar to a social services shelter. Mar and her family were accepted to reside at the shelter. The family moved in, dividing its time between the shelter and another family member's home a few blocks away. Shelter living was difficult, especially for Baby Ray. It was noisy, stuffy and crowded. Baby Ray cried incessantly.

"I told [the shelter manager] that we could not stay in the crowded shelter because my son would not be comfortable in that situation. I told her that my son, being the way he was, could not stay at the shelter, not among many people. He would cry all night long. He would cry and cry because of pain." (Mar)

Shelter staff assisted Mar with an application for more permanent housing. To be eligible, however, the family needed to reside most nights at the shelter, rather than with their nearby family member. The family felt they had no choice so they moved full-time into the shelter. To be closer to his family, Ren resigned from his airport job, taking employment at a restaurant in Waikiki.

Mar and Ren took turns caring for the children. Each morning, the family walked to the uncle's apartment to shower, eat and rest. Mar would take Baby Ray to his appointments, while Ren cared for Kate. Ren would catch up on his sleep intermittently throughout the day. In the late afternoons, the family walked back to the shelter and Ren departed on the bus for work, where he worked from 5:00 p.m. to 2:00 a.m. If able, he caught a bus back to the shelter. If he

was delayed and missed the bus, however, he walked the several miles to the shelter or waited for the 5:00 a.m. bus.

During the time of their residency at the shelter, the Healers doctors scheduled a surgery for Baby Ray to undergo a spinal fusion. The surgery was successful, but the living situation was of concern. The hospital staff did not want to discharge Baby Ray back to the shelter. In their estimation, it was not appropriate for Baby Ray's recovery.

"We stayed at Healers for two months… We were late (discharged) because they (Healers) knew that we were staying at the shelter. The doctor said he did not want to discharge him (my son) to the shelter because the (surgical wound) might get infected." (Mar)

The Healers social workers provided a supportive document to help accelerate the housing placement process for the family. With the assistance of the social workers, the family secured transitional housing at Gateway Apartment, a transitional housing program.

The Gateway unit was a studio apartment — consisting of a cramped room containing a mattress on the floor where all four family members slept. It also included a small kitchen and bathroom with shower. For all of its shortcomings, Mar and Ren preferred this transitional housing to the shelter because of the privacy it afforded.

"It was much easier there because we were on our own, in our own place, but it was only for one year. I was able to rest when my husband goes to work and my daughter went to pre-school." (Mar)

After living in the shelter and then transitional housing for nearly three years, in 2010 the family was relocated to a 3-bedroom apartment at a public housing unit in Kalihi where they live until today. Mar and Ren are grateful and pleased with the new accommodation. The children have bedrooms of their own.

"I am able to take care of my children and family. When I first came I felt so frustrated and helpless. Everything was difficult. I did not know where to go. My husband is working. We have a car and an affordable place. Before my husband would work until very late and would wait overnight for the bus to start servicing in the morning to come back home." (Mar)

Mar's father was able to visit for several months before his death. Ren's parents, too, came from Chuuk to spend time with their grandchildren. Mar and Ren purchased a pickup truck which allowed them to become more active in family and community affairs — visiting families and providing them with transportation, attending church events, assisting with church fundraising, and participating in birthday parties and funerals.

Ren joined several Chuukese family "insurance networks." He explained the functions of these networks, which are usually created along traditional connections:

"For the big expenses like funerals, the Chuukese people have these insurance networks that families participate in. On my side, I have a small one with my father's relatives. There are two that I participate in. There is one big one from our other side of the family. For example, if there is a funeral and we have about 80 families participating, each family would put down $50 each. So, all of that money collected will go to support the family of the deceased. But there are also many other families that come to help out by donating money. All of that to take care of the expenses… I've seen how important those kind of help are to our people. Without them no one can afford the expensive burdens of funerals. Many people rely on this because they know that every heavy burden is shared in this network." (Ren)

Kate enrolled in Roadside Elementary School adjacent to the Ali'i housing. Mar walked with Kate to school while Ren stayed home to watch Ray. Ray had largely recovered from his surgery. His bouts of crying subsided and his general health improved. He remained limited in

movement and coordination of his legs, however. The family received support from the home visitation staff of another nearby community clinic. Ray received physical and speech therapy, including an adapted chair. Healers Hospital provided a wheelchair. Mar appreciated the support from the clinic.

"The service providers were very helpful with providing us assistance with my child. They helped us apply for housing and began the medical process for Ray, especially the pre-school services at the clinic. They did home visits with our son and brought a lot of things that we needed. They brought Ray shoes and braces for his legs … They helped him with physical therapy and other needs like sitting chairs and other equipment. With the chair, I was able to put him in there and work in the house, doing other chores while he is able to sit up and play with his toys. It was safer for him. They would also provide respite service to help me out." (Mar)

Mar quickly learned how to do things on her own: "Once I get to understand how to get from place to place I was able to go to the appointments by myself. I understood what the doctors told me. We would catch the bus when our relatives were busy or at work." She was also able to help other families that recently arrived in Hawaii: "I help a lot of the new people who just came from home. I take them to their appointments and show them where to go to get services and help."

In 2011, Ray started elementary school. Mar accompanied Ray to school, volunteering in his classroom. She attended parent-teacher conferences and various school activities. Later, she was hired as a teacher's aide to work with immigrant students. She was then hired as a special education teacher aide, which she continues to the present: "Oh, I became a Special Education school aid. So now, what I'm doing is working with the ELL students who are slow in progressing. They give me the fourth grade."

Mar works with students from different ethnic backgrounds, including Chuukese. She noticed the challenges that the Chuukese students were facing in their classes: “If they don't understand anything the teacher say, I relay that to the teacher so the teacher can explain more… I guess if I was not there, the student would be just sitting around not knowing what's going on.”

“The teachers would tell me how proud they are of the students. The students showed a lot of difference/improvement in his learning.”

She talked about a student she was very proud of, who was a new arrival from Chuuk.

“The school put her in second grade so she was lost. I helped her quite a bit. She improved a lot. They put her in another school but she cried and returned back to our school because she felt comfortable with me helping her.” (Mar)

Mar has opportunities to observe Ray’s treatment at school. Ray thrives as a good student earning high marks on his school report cards. He has a friendly competition with his sister Kate who is also an honors student in their school.

One day during a fire drill, however, Mar noticed that Ray was not among the students filing out onto the playing field. She confronted her son’s teacher, asking about Ray’s whereabouts. The teacher responded that Ray had been excused from the activity to be left alone in his classroom during the event. Mar protested this decision and reported the incident to the principal, insisting that Ray not be treated differently because of his special needs, “I know my son has disability but I treat him like he does not have any… Because I want my child to be treated just like everybody else.”

Two years ago, Ray underwent surgery to permit him to sit upright with less strain and pain. The surgery was successful and now Ray can pull himself up and walk short distances with minimal assistance.

Last year, his uncles invited him to visit relatives in Washington State, where he became an avid fan of the Seahawks football team, wearing a Seahawks jersey and proudly displaying their banner. Upon his return to Hawai‘i, he enjoyed going to the beach with his family and spending Sundays at the movies with Ren. This fall, Ray began the 6th grade at a new school, a middle school in Kalihi.

Faith's Story

Betty was born on the main island of Weno in Chuuk State. Her parents originally came from a small island in the Mortlocks — which Betty identified as her spiritual homeland. Betty was married and the mother of six children. She and her family had lived and worked in Pohnpei for 10 years when her seventh child, Faith, was born in a private Pohnpei clinic in December 2016. During her pregnancy, Betty suspected that something was amiss. Betty claimed she was fatigued and prone to infection. She missed some days of work which had never happened before.

"It was slightly different with Faith, my youngest child. Faith was different from her siblings. When I was pregnant with Faith I was hospitalized twice because of pain. During my two visits, the doctors would prescribe me medicine and I would ask whether it would affect my child or not… My previous pregnancies were very simple. No complications. I never got sick or had any health issues, except for Faith." (Betty)

When Faith was born, the doctors immediately noted the abnormality. Faith was diagnosed with hydrocephalus — an accumulation of cerebral spinal fluid in her brain.

"The doctor told me that my child's head would continue to grow bigger for her size. I asked how did he know and he said because there was a build-up of fluid in my child's head around the brain. [I learned that the name of the condition Hydrocephalus.] But I did not believe

the doctor. After one day we left the clinic and I started to observe the baby. Then I realized the doctor might be right. Her head was growing bigger and was a little lopsided. One side was growing bigger, that I started thinking about what to do to help my baby." (Betty)

Betty had not planned on moving her family to Hawai‘i, but she saw no choice upon learning of Faith's medical condition, which could not be adequately treated in the FSM.

"I would take her to her baby appointments where the doctor would measure and monitor the growth of her head and they told me that her head was continuing to grow. Then I asked them if there is any kind of help that they could provide for my daughter. They said they could not do anything because they don't have the equipment to do anything for the baby. They told me that they could only help in referring the baby to outside of Pohnpei for additional medical care." (Betty)

The medical personnel advised the family to seek overseas treatment either in the Philippines or Hawai‘i. Betty had family connections in Hawai‘i, but not in the Philippines, so Hawai‘i seemed to be the only choice. Betty's parents were residing in Hawai‘i with Betty's older sister. They too had come to Hawai‘i due to health concerns that could not be treated in the FSM. Betty's father had chronic diabetes and her mother suffered from a debilitating heart condition.

Betty approached her insurance providers in Pohnpei to request financial support for Faith's referral to Hawai‘i. The insurance company declined coverage, however, claiming that Faith's insurance excluded pre-existing conditions. Betty spoke with governmental officials, but they refused to intervene.

"I called the government insurance I was under and they told me that they could not help my daughter. They claimed that my daughter's condition was a pre-existing condition and could

not be covered under the insurance policy. The policy defines any illness or condition that the baby is born with a pre-existing condition. If the baby was born healthy but then gotten sick then that would be qualified for coverage under the insurance policy." (Betty)

"I contacted my parents who are [in Hawai'i] and told them what had happened. They said that they were going to try to raise the money to bring my baby and me to Hawai'i for treatment. They began to do community fundraising among our relatives and friends. They worked very hard to do several fundraising to help pay for our travel here. I was grateful that they were able to raise the money for our travel here." (Betty)

In time the family was able to raise sufficient money to purchase airline tickets for Betty, Faith, and two of her other children. Betty arrived with the children in January 2017. They moved in with Betty's sister, sister's husband, their child and her parents, into a 2-room apartment on Date Street in Honolulu.

Two days after their arrival, a relative took Betty and Faith to a clinic in Kalihi for a walk-in appointment. The clinic staff immediately initiated the process of applying for family assistance, including health insurance. Betty was referred to a counselor at the Palama Settlement to begin the process of applying for housing and job training. Betty provided the Paradise Community Center medical staff with Faith's medical records from Pohnpei. Shortly after, Faith was referred both to Sunshine Hospital for Women and Children and Healers Hospital for additional testing, including a CT scan.

"I also encouraged the staff to call the clinic back home to verify the information. They called the clinic back home and the doctors there further explained about the baby's condition… They referred us to Healers hospital for the baby's MRI. And again we got referred to Sunshine after the scan for other tests. So far they said that the region of the brain that had fluid is still

okay. The doctors decided it best to wait six months to see if Faith's body would absorb the fluid build-up without resorting to surgery. Faith's next appointment is in October 2017, at which time it will be decided whether or not her doctors need to insert shunts to drain the fluid." (Betty)

While Betty was taking Faith to her medical appointments, the family's housing situation became critical. The landlord claimed that Betty's sister and husband had failed to re-certify the lease on their apartment. Although Betty's sister contested the accusation — claiming to have given the renewal application to someone else in the office — the landlord proceeded with an eviction. The family was to move out by the end of April 2017 without recourse.

Betty assumed responsibility to find housing for her parents, her three children and herself. Her sister and her family agreed to search independently. Betty consulted social workers and she searched printed advertisements for housing rentals. She could not find any affordable places. With just two days before imminent eviction, the situation became desperate. Betty had heard about Micronesian families living in tents on sidewalks in Hawai‘i, which would be unacceptable for her family. The social worker informed Betty that she should consider living in a shelter as an only option.

"That person asked me if I was willing to stay in a shelter. I asked him what is a shelter? He laughed at me and told me that he thought that I would not like the shelter. I said why? He told me that it's crowded and noisy. I asked if I had any choice at this point. He told me that I could live on the sidewalk under the tents. He also told me that there are a lot of Chuukese at the shelter. So, I told him that since he told me all these things about the shelter but I did not see any alternative. But if that's where I need to start then I will go to the shelter." (Betty)

The counselor made an appointment for Betty with a church-based organization to inquire about a new shelter that had recently opened. As luck would have it, the shelter informed Betty that they had an opening for just one more family. They could accommodate Betty, her children, and her parents. Betty felt relieved but also anxious. She had found shelter for her family but had no idea of what to expect.

The shelter was located at the western end of a large parking lot. Betty and her family arrived by taxicab. Mistakenly, they disembarked at the wrong end of the parking lot in front of a nice big modern building. Leaving her family on the sidewalk, Betty excitedly approached the front doors. The building was modern, clean and inviting. All of the doors were locked, however. There was no one to give her advice or direction. Betty phoned the shelter and was told to walk to the opposite end of the parking lot. She advised her family to stay put while she walked to the shelter building by herself. The shelter was a former warehouse converted in 2016 to house families with children.

" My heart nearly stopped when I saw it. It was shocking to see the place where we would be living. I could not hide my tears of worry and fear when I entered the shelter." (Betty)

The staff was welcoming and understanding, assuring her that they understood her anxiety. Betty could give the shelter a try; but if she did not like it, she and her family were free to leave. Betty filled out the paperwork and returned to the parking lot to retrieve her family, trying her best to mask her fears and tears.

"I went back and brought my family to the shelter. I tried not to face them because I did not want them to see my tears." (Betty)

It took several days for the family to acclimate to living in the shelter. The staff was helpful and caring, offering services and programs to help the family with health insurance,

housing applications, educational and recreational programs, and childcare. The shelter consisted of a large rectangular space divided into cubicles — one cubicle per family. Communal bathrooms and showers were located at one end.

Betty's oldest daughter, Peggy, attended high school. The second daughter, Lisa, was three years old so she stayed with Betty's parents at the shelter during the day. When Betty was out running family errands, Peggy and her parents cared for Baby Faith. Staff from Children with Disabilities Association provided physical therapy and an adapted seating chair to help her sit up during feeding. The University of Hawai‘i medical school provided medical services for all shelter residents through a mobile team of medical students and practitioners. Betty was very grateful for these services. As payback, she assisted with cleanup and chores around the shelter.

Soon after their arrival, Betty began job hunting. She inquired about employment at the public schools located nearby the shelter. At one of the elementary schools close by the shelter, she learned of a position available as a meal ticket counter. She applied and a few days later received a call for an interview. After examining her resume, the principal realized that Betty was an experienced schoolteacher. He asked her to interview for a teacher's aide position. She was immediately hired to work mornings, which left her afternoons free to arrange medical appointments for Faith and her parents.

Recently, Betty's mother was hospitalized. She now requires constant attention after discharge. Betty's sister and her husband have invited the entire family to reside with them in their new residence on Vineyard Boulevard. Betty has informed the shelter staff that she and her family will be moving out to more adequately care for her mother. Betty's employment as teacher aide was renewed and extended into 2017-18 school year.

CHAPTER 5: DATA ANALYSIS

This chapter identifies family-specific themes that lend themselves to identifying a larger pattern of the Chuukese migration and disability experience. Even though specific themes are identified or highlighted in each family story, it should be noted that these themes are also found in all three family stories. Each family had a unique experience but also shared strong common strands in their experiences. To lend credibility, the themes were triangulated using multiple sources of data, including findings from individual interviews, focus groups, and document reviews. In this chapter, I will highlight these individual family themes and cross-case themes with references from the family stories to emphasize these thematic connections.

Case 1. TJ's Family

Table 4 summarizes the themes identified for each family, and the common themes that emerged in the cross-case analysis. Among the driving themes for TJ's family were the importance of *cultural heritage* and relational supports; *obstacles* associated with disability and urban life; and angst associated with uprootedness, migration and homelessness. *Resilience* was the final theme in this family story.

Cultural Heritage and Interpersonal Relationships

The Chuukese culture is essentially communal in that it depends on its network of connections for support, be it family members, eterenges (extended family), ainang (clans) or newly created friendship and/or support individuals or groups (Flinn, 1990; Goodenough, 1957; Marshall, 1977). Through explicit and implicit roles assigned within families and clans, individuals are responsible for one another's wellbeing. This became evident as TJ's family migrated from place to place, including living in Weno, the Mortlocks, Pohnpei, Saipan, Guam and lastly Hawai‘i. In every locale, family members -- no matter how "extended" -- were

Table 4

Themes From Stories

TJ's Family	Ray's Family	Faith's Family	Cross: English	Cross: Chuukese
Cultural heritage and relationships	Centrality of Family Professional Support	Nurturing Community	Identity, Faith, and Courage	Muirmuir waom
Barriers and General Angst	Challenges in communication & transitions	Chronic Stress	Existential insecurities	Matauen Apungurosh
Resilience	Reciprocity	Reciprocity, Resilience, and Determination	Inclusion, Nurturing, Reciprocity, and Cultural continuity	Achu Matau

expected to feed and shelter the family. In the individual interviews and focus group, Rita put strong emphasis on how much she relied on her family members and others to address TJ's health needs, education advocacy, and housing support.

Rita gave birth to TJ, her first born, in Pohnpei. During their stay in Pohnpei, members of Rita's extended family sustained her and her husband Phillip. Upon returning to Weno, Phillip's extended family became hosts and caretakers. Both Rita and Phillip self-identified with the Mortlocks islands, which were the home islands of their parents -- with unique culture and language. Rita and Phillip traveled to the Mortlocks islands with TJ — taking some risk to do so given the fragile nature of his health — in order for TJ to become acquainted with his grandparents and to learn, firsthand, some of the stories and songs of his grandfather -- stories and songs that TJ remembers to this day.

Later, when TJ suffered from a kidney ailment, Rita's cousin — a medical officer in Chuuk — advised the family to move to Saipan for his surgery. Upon arrival in Saipan, Rita's older sister, Jenny, helped the family to navigate both the medical and educational systems to obtain appropriate services for TJ. Rita credits Jenny as the person who taught her how to advocate for TJ through the maze of Saipan's special education system. Sometime later, after Rita and TJ were discharged from Healers Hospital in Honolulu, it was Rita's cousin who accommodated them in her apartment. Later, an uncle, James, provided accommodation until the family was compelled to move into a homeless shelter.

Through every step of their journey, extended family members sustained TJ's family; something which they attributed both to family love and cultural obligation. In recent years, the network has expanded to include relationships beyond family and clan, including

select medical staff from Healers Hospital and the Paradise Community Center Medical Center, social workers associated with Gateway Housing, and several public school teachers.

Obstacles and Barriers

TJ's family encountered obstacles and barriers related both to TJ's health and disability requirements, and to the family's everyday existential issues related to urban survival – migrant experience, language and cultural mismatch, and generalized urban poverty.

Health and disability. Soon after TJ's birth, Rita and Phillip recognized clues that their lives would be complicated by TJ's disability. Early on, TJ was diagnosed with cerebral palsy, and although neither Rita nor Phillip knew of its implications for TJ's self-care, mobility or communication, they soon gathered from Chuukese medical authorities that TJ was a "special" and "fragile" child. TJ's diagnosis with kidney failure brought home the fact that the family could not remain in Chuuk if their baby was to survive. Numerous moves and surgeries followed, first in Saipan and then Honolulu.

While living in Honolulu, TJ's recovery from surgery and overall health were put at risk by the family's housing situation. The homeless shelter where the family was located was noisy, stuffy and hot. It was an inappropriate place for a medically fragile child to recover from major surgery. This unhealthy housing situation put additional pressure on Rita, Phillip and their associated social workers to seek remedy, which was complicated by the housing shortage in Honolulu and restrictions in public housing that prohibited their family members from inviting them in.

Although Rita wanted TJ to attend school, more than anything she wanted him to be safe. On several occasions, he was mishandled by school staff and left unattended on the playground and at the bus stop. Although Rita learned to speak up and advocate for TJ, it proved

to be an ongoing source of anxiety. For both cultural and language reasons, communication with school authorities remained fraught with difficulty. For this and other reasons, Rita reported a high degree of angst that dominated the family's experience relative to TJ's disability. Although this stress surfaced in Saipan with TJ's kidney surgery, it became more pervasive upon arriving in Hawai'i. Would TJ become ill or die? Would he be injured or neglected at school or on the school bus?

Urban poverty. TJ's family's saga to find appropriate housing in Honolulu is an oft-repeated theme expressed among Micronesian migrants in Hawai'i. Due to housing restrictions, the doors of public housing are closed, even when family members were eager to open them. On occasions, TJ's family literally hid inside of relatives' apartments, the children not even attending school out of fear they would be spotted by housing authorities. Twice TJ's family lived in the IHS homeless shelter, interrupted by periods in short-term transitional housing. The transitional studio apartments accommodated as many as eight family members — all sleeping and eating in a single room.

Transportation was also a difficult challenge. The Honolulu bus system is dependable and comprehensive, but its hours — especially at night — are limited. Phillip worked in Waikiki until 2:00 AM. If he was delayed in getting off his shift -- as happened -- he would miss his bus and have to walk several miles to the homeless shelter, arriving at 5:00 AM. The buses also proved difficult for Rita, as her children attended two different schools, which made the logistics of riding buses difficult when taking her children to school and picking them up. On one occasion, Rita missed an IEP meeting because of this. She found it easier to walk than take the bus, but arrived too late and was scolded by school authorities for doing so. In fact, the team

filled out TJ's IEP in her absence, which she refused to sign -- requiring additional school visits and consultations.

When the family secured transitional housing in Waianae the housing situation improved. Finally, they had bedrooms for the children. The transportation system, however, worsened. Waiʻanae High School refused to accommodate TJ -- stating that they were unable to manage and administer his medications. The school insisted instead that TJ commute to McKinley High School in Honolulu -- an hour and a half's bus ride away. This required the family to depart Waiʻanae at 5:00 AM and not return until bedtime. The situation was untenable. After a month, Rita pulled TJ out of school and kept him home for the duration of the spring term. She was not contacted by school authorities to remedy the situation.

Generalized angst. It is one thing to move to a new and strange place out of choice, i.e., the choice to better one's life and improve opportunities. It is quite another to have no choice but to move. Rita and Phillip fell into this latter category: they felt they had no choice but to leave Chuuk and seek medical help elsewhere. If TJ were to survive, the family would have to move, first to Saipan and then Hawaiʻi. "Life or death" was not a choice, but a mandate. At the advice of Healers physicians, the family moved to Honolulu. Rita and Phillip chose to come as a family; to stay together; and face whatever was to come. This included living in homeless shelters, transitional housing and cramped studio apartments — none of which felt like home. Rita and Phillip both spoke of the angst of "being moved around;" a feeling of helplessness, an emptiness.

Resilience

Through it all, Rita, Phillip and their family have maintained cohesion and optimism. Rita and Phillip both reported a growing bond as a family. Their children are healthy

and are being educated. Phillip remains employed. They have secured subsidized housing in the city of Honolulu and are active in their Chuukese church and community. They are appreciative of the professionals who have helped them. Their home is open to family and friends. At this time at least, the angst of migration appears to have subsided.

Case 2. Ray's Family

Among the driving themes for Ray's family are family/professional relations and support; challenges in communication and transitions associated with Baby Ray's health and disability, and reciprocity.

Family and Professional Relations and Supports

Centrality of family. The significance of family support cannot be overstated. When Chuuk state refused to pay for travel expenses to move the family to Hawai'i to get medical care for their son, Mar's and Ren's families contributed the money. Upon arriving in Hawai'i, extended family offered housing and guidance to secure medical services in clinics and hospitals.

Although Baby Ray's care has always been Mar's primary responsibility, Ren (Mar's husband) and Kate (Ray's sister) have helped tremendously. When Mar is outside of the home, Ren assumes the primary care responsibilities. On Sundays, Ren and Baby Ray go to the movies together — providing some respite for Mar. When both parents are absent, Kate becomes Ray's babysitter.

Ren and Mar now play a reciprocal role within the extended family — providing a variety of financial, physical and social supports to family members back home in Chuuk and Guam, as well as to those traveling through or residing in Hawai'i. As they are able, they provide money, transportation, food and shelter. They take relatives to appointments and family events. They are active in family and church fundraising — including funerals, birthdays and

weddings. Most recently, the extended family paid the expenses for Ray to visit Mar's siblings in Washington State.

Professional supports. Ren and Mar have developed a strong loyalty to health and social services professionals in Honolulu. Before moving to Hawai‘i, they benefitted from valued counsel from the Healers Hospital visiting team in Chuuk. Subsequently, Ray's hospitalizations and regular appointments at Healers educated the family about his health and well-being. Besides life-saving surgeries, the Healers have supplied Ray with two wheelchairs.

Similarly, Ren and Mar are grateful to the educators, and health and social services providers at Kona and Paradise Community Center. The Kona staff visited Baby Ray at home, provided donated clothing and supplies, transported the family on occasions to appointments, and provided physical and speech therapy for him. The clinic staff provided primary health services as well as social services such as public health insurance, temporary financial assistance and housing applications. The social workers at the clinic directed the family to housing opportunities, including the homeless shelter and transitional housing.

Challenges in Communication and Transition

Failures of communication. At the time of Baby Ray's birth and in ensuing months, Chuukese medical authorities did not inform Mar or Ren of Baby Ray's medical condition or prognosis. After months of delay, they informed Mar's father-in-law, rather than communicating with Mar and Ren themselves. In the interim, Mar and Ren came to the realization on their own that Baby Ray was not developing normally — noting his weight loss and the instability of his head and neck. The failure of the Chuukese medical authorities to communicate clearly and directly with Mar and Ren remains a mystery to this day. It was a great source of anxiety for Ray's parents.

The Healers physicians informed the couple of the baby's diagnosis. Upon receiving the news, Mar and Ren determined to uproot their family and move to Hawai'i. They had little or no confidence in the Chuukese medical authorities — believing they were neither timely, nor transparent/forthright in their behavior. The transition to Hawai'i was made even more difficult because the Chuukese medical authorities refused to provide Baby Ray's medical records to the Healers team.

Difficult transitions. It was two years before Baby Ray underwent spinal fusion surgery at Healers Hospital. Throughout that time, Baby Ray's health was precarious. He cried incessantly. Mar reported experiencing profound stress in attending to his needs.

Mar, Ren and their children resided with relatives in public housing — both in Mauka Housing and Ali'i. They lived in fear that neighbors would hear Baby Ray's cries and report them to public housing officials who in turn would charge them with illegal occupancy — resulting in eviction for the entire family including the relatives who invited them to stay.

The family struggled without adequate public services. Although they resided legally in the United States, they were not eligible for Medicaid, Medicare or Social Security Insurance. Since no one in this family was a U.S. citizen, they were not eligible for the safety net programs, such as Temporary Assistance for Needy Family (TANF) and Supplemental Nutrition Assistance Program (SNAP), to ensure an adequate and healthy diet.

For three years Mar, Ren and their children lived in the shadows — moving from one family member's house to another, avoiding detection by housing authorities. Finally, they secured space, first in a homeless shelter and then the Gateway transitional home. The living conditions in both were difficult — stuffy, cramped and noisy. Ren depended upon The Bus for transportation to and from work — walking up to 6 miles when The Bus was not running.

Reciprocity

Mar wanted to give back to her community in a professional capacity. She first volunteered in her children's schools and then became a teacher's aid and tutor. She spoke of a particular Chuukese student whom she helped to overcome significant obstacles. Mar helped parents and school officials to connect with one another — having become a resource person for the school and parents of various ethnic backgrounds.

Mar functions as a positive role model for parents of children with and without disabilities. Both Ray and Kate are doing well in school as Mar and Ren diligently provide positive supports for success. Mar speaks to other parents of her hope for Ray to become educated and to overcome any stigma of being disabled. She emphasizes that there is no shame in disability.

Case 3. Faith's Family

In December 2016, Baby Faith was born at the Genesis Clinic in Pohnpei, FSM. As evidenced at her birth, Faith was diagnosed with hydrocephalus. Her physicians recommended that she immediately be transported to Honolulu for medical treatment. Faith's mother, Betty, decided to move to Hawai'i with Faith and three other children, leaving her husband to remain in Pohnpei to work and care for their three other children. Betty's extended family in Honolulu raised the funds to support their travel, including providing them with shelter upon their arrival. Soon after, however, Betty and her family faced a housing crisis, which was ameliorated by their moving into a homeless shelter.

Although their housing situation remains precarious to this day, Betty remains optimistic and resilient. Faith's family experience was centered around three themes: nurturing family community; reciprocity, resilience and determination; and chronic stress.

Nurturing Family Community

Betty recognizes and appreciates family and community supports. When Betty is at work, her parents and oldest daughter care for Faith. Faith brings great joy to the family. She is fully included in their personal and public lives. Betty commends the shelter staff for their care and kindness — not just for their kindness to Faith but to her parents as well. Betty's mother, for example, walks slowly with a walker. Shelter staff members accompany her to the bathroom, exceeding their normal expectations.

Betty meets with outreach teams from social and legal services to apply for housing and disability services. She maintains regular and trusting relationships with the professionals — recognizing the importance of their work; wanting to maintain their allegiance and support. This growing support network results in nurturing and caring supports for Betty's family.

Betty's sister and her husband have now located a 2-bedroom apartment near Honolulu's Chinatown. Because of their mother's worsening health condition, Betty and her sister have decided to move in together again to provide better care. In short, Betty is a team player who depends upon others both in her family and in community.

Reciprocity, Resilience, and Determination

Betty has always been strong-willed and determined. She earned a Bachelor of Arts degree from a University of Guam program offered at the College of Micronesia (COM-FSM), became the principal breadwinner of a growing family, secured employment as a professional teacher in Pohnpei, and became active in the Parent-Teacher Association (PTA) at her children's school. She was an active public figure in her church and village.

"Giving up" was never an option, even when Betty was faced with Faith's diagnosis. Betty would do everything necessary to secure appropriate medical care for her

daughter. She approached her extended family for financial support and secured it. Leaving her husband and three of her children at home, she embarked into the unknown, often dependent on the kindness of strangers, including social service staff members.

Faith's healthcare needs have also brought the family into close communication with helpful service providers associated both with the Disability Friends Society and several public agencies. Therapists visit the family weekly (both at the homeless shelter and now at the Chinatown apartment) to teach feeding, positioning and movement, which are critical for Faith's development. Betty recognizes the importance of these services and conveys her appreciation to the teams. She volunteers to translate and mentor other families in similar situations. Betty also recognized the kindness of shelter staff and expresses her appreciation by volunteering with chores around the shelter.

Within months of arriving in Hawai‘i, Betty secured employment with the Hawai‘i Department of Education as a teacher's aide. She educated herself about Faith's medical condition by studying on the Internet and engaging in dialogue with Faith's medical team. Betty maintained meticulous files, notes and calendars of medical appointments, obligations and documents. She learned to take public bus transportation and navigate the complicated social services bureaucracy to secure health insurance for her children. Betty now speaks of returning to university to study special education to become a teacher.

Betty and her family are active in Chuukese Catholic church services and activities. Besides Sunday services, they join fellow island worshipers in public parks on Wednesday evenings taking turns to lead the services. Relatives from their island region invite them to birthdays, weddings and fundraisers in which everyone contributes items for raffle contests. Some bring breadfruit, taro and fish to add home island flavor to the events. The family

has joined a network of Chuukese contributors to a funeral insurance program which provides death benefits (covering the costs of transportation and funeral services) to bring the deceased back to Chuuk state for burial.

Chronic Stress

Betty experienced a difficult pregnancy with Faith, her seventh child. She was hospitalized twice during the pregnancy. As a newborn, Faith's medical fragility was apparent. Without question, Betty knew what she had to do; she took leave from her position as an elementary school teacher in Pohnpei, and secured funding from her family to bring Faith and three of her other children to Hawai‘i. Government insurance benefits from the Federated States of Micronesia (FSM) were denied, as baby Faith was declared to present a pre-existing condition which excluded her from any insurance coverage. All travel and medical expenses were to be borne by the family. The loss of employment income and the travel expenses stretched the family's resources to the limits.

To make matters worse, Betty's sister was already dealing with the healthcare needs of their parents. Both father and mother had moved to Hawai‘i to receive treatments for diabetes and heart disease. Betty's sister, her husband and her two children moved with them to provide care. Baby Faith's healthcare needs, in addition to the costs associated with moving, added further stress to this already difficult situation. Betty's sister remained optimistic and welcoming as Betty and her four children moved in, too. Ten people were now residing in a 2-bedroom apartment, including Faith, a medically fragile child. Not long after, the entire family faced eviction; no housing alternatives were apparent. "Are we destined to become homeless?" Betty wondered aloud.

Betty and her sister split up in search of housing. Betty's sister, her husband and children secured alternative housing. Betty, her children and her parents secured accommodation in a homeless shelter. Betty was distraught. "I was overwhelmed with anxiety unlike anything I had ever experienced before; trying my best to hide my tears and fears from the family." To this day, Betty has never divulged this emotional toll to her parents.

Cross-Case Analysis

TJ's, Ray's and Faith's families share common bonds and experiences in terms of culture, disability, uprootedness and resilience. In this chapter common themes are bundled in a culturally specific way to be understood from the Chuukese indigenous tradition of Wayfinding. For the ancients, scarcity of resources and famine might necessitate an oceanic journey. In this contemporary research, it was the birth of a child who could not be treated and nurtured at home.

Muriurin Waom: Identity, Faith, and Courage

Murimurin Waom literally means fixing the reference points to determine in which direction one's canoe (waomw) should travel in the ocean. Navigators usually use landmarks (e.g., islands) and celestial movements as the reference points (muir), with the act of setting the course called muirmuir. Muir can also be figuratively defined, as the purposes for travel, such as famine, conflict, and other events. By using "home" as a muir, the navigator can determine direction, and is reminded of why he is voyaging. Events or issues of need at home drive the journey. This birth of a child with disability, because of its disruptive nature, becomes the reference point, the guiding purposes for travel, or muir for the family to journey to Hawai'i. Three concepts are embedded within this muir: identity, faith and courage.

Identity. All three of the mothers whom I interviewed exhibited a strong sense of identity with their ancestral homelands — identifying with family members living and gone.

Mar and Betty were neither born nor raised on their ancestral home islands. As children they occasionally visited the islands, and much of their identity was shaped from stories, songs and recollections. All three mothers have lived their adult lives away from ancestral islands. However, they all report having profound memories of those places including family histories and genealogies — even maintaining the distinguishable island accents. These enduring memories have proven formative in their social development — defining where they are from, who they are related to, and who they can rely upon. Their ancestry represents an invisible, living web of culture that underlies and defines their identities: "Where I am from" and "Who I am" — Murimurin Waom.

Families are secure in their cultural heritage, ancestry and family ties. They know where they come from; and they know their way home. Migration — better expressed as wayfinding — has been a fact of island life since time immemorial — including the contemporary practice of going "off island" for school, work, military service or medical treatment. No one truly leaves and everyone returns. The people journeys knowing they always have a place called home; a place to return to, to be buried.

Faith. All three of the families are faithful. Their faith consists both of belief and practice — belief in God and family (including the extended community) and a practice of reciprocity and interdependence. They are Catholic both in belief and community — regularly attending church services, Sunday schools, prayer groups, novenas, choir practices, church historical anniversaries and other religious conventions. In times of need, they pray to God for divine intervention — drawing strength from enduring faith in relationships. Although they may be challenged beyond their capacity, they believe that God and family will provide. Extended families willingly raise money; provide sustenance and shelter; and risk their own safety,

comfort and wellbeing to ease the pain and suffering of their fellows. The inherent goodness and obligation of family is a fundamental teaching of the Catholic Church and the Chuukese Culture.

Courage. Courage is embedded in the above. It is constructed through *identity* and *faith.* Just as ancestral wayfinders drew upon courage to uproot and sail into the unknown, so these contemporary sojourners draw upon their courage to board the airlines for Hawai'i; traveling without money or material resources, arriving only with suitcases and bags in hand. They are aware only through movies and television of escalators, freeways, skyscrapers, supermarkets, malls and the myriad urban ills awaiting. Their courage continues to sustain them on a daily basis as they face challenges in school, housing, healthcare, and employment. Courage is buoyed up by faith in God and family.

Matauen Apungurosh: Existential Insecurities

Matauen Apungurosh literally means "Dark Ocean." The Matauen Apungurosh refers to ocean passages and seascapes that are strange and unfamiliar to the Wayfinder and seemingly impossible to navigate. Paselo describes the condition of being "adrift," to have no control over the movement or directionality of the canoe — a helpless situation requiring great faith and courage.

Disabling conditions. The precipitating existential threat for each of the families was the birth of a child with fragile health conditions and physical disabilities. The babies were born in the FSM where medical services were inadequate to serve children with significant health care needs. Although the parents realized their children needed special attention, they were uninformed or ill-informed regarding diagnosis and prognosis. Communications between medical authorities and the parents were inadequate and confusing. It was not until the visiting Healers medical teams arrived that communication became clearer and the parents understood

that the children required medical treatments in Hawai‘i. To compound matters, the FSM government refused to provide insurance coverage for any related expenses, including costs of transportation, off-island medical treatment, or other family supports. This denial was justified by determining the children to have pre-existing conditions — i.e., disability that occurs during pregnancy is pre-existing to the birth and, hence, uncovered by government insurance.

Urban woes. The threat of homelessness loomed (and still does) as an overarching existential threat. Although relatives residing in Hawai‘i public housing were always willing to open their doors to recent arrivals, restrictive housing codes put such displays of hospitality at risk or prevented it altogether. Such restrictions left the families in a perpetual state of limbo — requiring that they hide from authorities, dodge inspectors, and move frequently from place to place. The fear was not simply that they themselves would be evicted, but that their hosting relatives would be evicted, too — and banned from future eligibility. As able, families occupied living room floors often crowded with 10 or more family members including a child with disability recovering from surgeries.

The families were also in and out of homeless shelters and transitional facilities — exacerbated by the fact that they were required to vacate the premises during the day — including elderly and frail parents and young and disabled children. The conditions in the shelters were difficult at night. They were noisy, hot and “public,” including congregate bathrooms unsuitable for children healing from surgeries and/or ill from other causes. TJ and Baby Ray cried incessantly for months. Fathers working night shifts were prohibited from entrance due to curfew requirements. Two of the mothers were hospitalized twice during their stays — with expensive health insurance through the Affordable Care Act, which caused them to default on their premium payments and receive letters from collectors. In short, the level of

stress attributable to this chronic housing and health crisis cannot be overstated — homelessness directly resulted in sleeplessness, weight loss, illness and fatigue for these mothers.

Achu Matau: Inclusion, Nurturing, and Cultural Continuity

Achu Matau literally means "Connecting Oceans." It is a Wayfinding term, which describes looking beyond the immediacy of place and time to identify patterns and relationships that are hidden beyond horizons. Navigators learn not to isolate individual islands, shoals, stars and swells, in favor of discerning patterns and relationships that are inclusive of a greater whole. In this metaphor, the individual becomes part of a larger group, acts within that group, is nurtured by the group, gives back to it, and in so doing becomes part of a history unbounded by place and time.

Inclusion. The concept of disability as a unique construct does not exist within the Chuukese worldview. The words for "disability" and "illness" are identical — and part of the fabric of the human condition: in life we experience joy, sorrow, illness/disability and death. Disability/illness provide families with opportunities to nurture, grow and honor God. Disability is not to be seen as weakness, omen, punishment or spell; nor is it to be understood as a signaling of diminished dreams. Families thrive because of such challenges, not in spite of them.

Nurturing. The three mothers (and older siblings) are the primary caretakers for younger children and frail elderly — both in the home and in interactions with public agencies. The women attend IEP and teacher/parent meetings. They volunteer in their children's classrooms. They interface with public agencies and "helping professionals." They take children and elderly to medical appointments and surgeries. Educated siblings are expected to provide language translation for family members in public encounters. Men are expected to work hard, be employed, working night shifts, weekends, and overtime as they are able.

Cultural continuity. These three families rely on their traditional family kinship networks that span from the ancestral homelands in the Mortlocks, to Weno, Pohnpei, Saipan, Guam, Hawai‘i, and throughout several states on the U.S. mainland. In Hawai‘i, these networks of extended kinship include family members, clan members from throughout Chuuk, Pohnpei, outer island of Yap, newly formed friendships, marriage, and other relations. Communication throughout this expanding network is possible through new media and the Internet. These connections are vital to sustain these families' cultures and relationships. Their travel to Hawai‘i in order to seek treatment and care for their children with special needs has expanded this Island network of kinship and provides a source of empowerment, sense of faith and courage in their identity for these families.

Triangulation

Triangulation ensures the internal validity or the "trustworthiness" of the data in qualitative studies (Merriam, 2001). This study used three points of triangulation to the primary source of personal interviews to corroborate the data: (a) focus group, (b) analysis of documents and other sources that pertain to topics brought up by family members during interviews, and (c) my own observation and position as a person with a disability, as a family member of a child with significant disability, and as a service provider (see Table 5).

Table 5: Data Triangulation: Sources of Verification

Primary Data Interview	Focus Group	Documentation	Observation
Birth History of Child	X	X	
Diagnosis	X	X	X
Family Network	X		X
Medical Experience	X		X
Housing	X	X	X
School Engagement	X	X	
Employment	X		X

When reviewing the semi-structured interview transcripts of the primary source data, it was possible to verify the stories through triangulation. For example, each semi-structured interview included an explanation of the child's birth experience. In the focus group, the families shared again about the birth of their children with special needs. All families have medical documentations of their children's diagnosis, which verified the information shared in the semi-structured interviews. They each spoke in the focus group about the circumstances of their children's development and their experiences finding out about their children's disabilities. In addition, the focus group gave them an opportunity to share their hardship and difficulty and the incredible support of their family network. I observed the efforts of the family networks, who sponsored several activities including birthday parties, barbecues, and fundraising during the data collection phase of the study.

The family's engagement with the medical and healthcare system in Hawai‘i was corroborated in shared stories during the focus group and by medical documentation such as letters from insurance companies informing the mothers that their insurance coverage under the ACA (or Obamacare) had been canceled. I also helped these families in their homes, in my professional capacity as a healthcare outreach worker, and at the shelter with enrollment and reenrollment on these medical coverage programs. The families kept appointment summaries from their children's hospital visits, which I was given permission to review. In addition, I observed the third family's appointment with visiting physical and speech therapists at the shelter.

Although I was not able to attend any of the families' IEP meetings, they discussed their experiences during the focus group and the first and second mothers also showed me copies of their sons' IEPs. The initial discussion of employment for the first two fathers and the second

and third mothers were brought up during the individual interviews and verified during the focus group. I also visited the worksites for the two fathers. I was treated to dinner at the restaurant where the first husband worked and I picked up some seafood from the fish market, where the second husband works.

Member Checking

Member checking is the process of allowing the participants to review the data and results, to ensure accuracy for the study. I met with family members separately to show them the stories, which involved oral interpretation of the English text into Mortlockese. I met separately with the mothers at a familiar restaurant. I showed them the stories and had them listen to the interviews to ensure that they were satisfied with the data and the interpretation in each story. I also called them on the phone to discuss several questions that were raised during the review and writing of the stories. All participants were satisfied with the data interpretation and the results of the study. This enhanced the internal validity of the study.

CHAPTER VI. DISCUSSION

I have presented the themes that emerged from each family's stories and across all three families to explore the motivational forces behind the families' decisions to move to Hawai'i and their thriving resilience to endure the challenges faced in Hawai'i. In this chapter, I will discuss: (a) the outcomes of his study, (b) the family themes, (c) the family themes and the research questions, (d) the methodological approach of the study, (e) the limitations of the study (f) implications for theory and research, (g) implications for practice, and (h) the lessons learned from the study.

Outcomes of the Study

This study addressed the primary research question: "What are the experiences of recent Chuukese migrant families of children with disabilities living in Hawai'i?" To answer this question, four outcomes were gleaned from the stories of these families' travels and the themes that come through from them. These outcomes can be generally identified as: (a) family heritage, (b) family resilience, (c) inclusion, and (d) cultural continuity.

Family Heritage

The first outcome demonstrated in this study is that these Chuukese families are deeply grounded in and enriched by their cultural heritage. They know their identity, a sense of who they are, what clan and island they belong to, and the family network they can count on for support. They understand, appreciate, and value a strong connection to their spirituality and their living community.

For Rita and Phillip, their family connection included Phillip's family on Weno, Rita's family in the Mortlocks, her relatives in Pohnpei, sister in Saipan, both parents' relatives in Guam, and members of Rita's extended family in Hawai'i. TJ's family relied on the strength of

his family's support to provide assistance when his health became critical. Rita and Phillip now contribute to that same family network by hosting members at their place and sponsoring family get-togethers. They participate in family events such as birthday parties and fundraisers, which are critical in maintaining strong connection and providing support for other family members in their network. They were able to bring TJ's grandfather to Hawai‘i to receive medical assistance. His presence also enhanced TJ's outcome by reconnecting him with grandfather and his storytelling.

Ray's family has roots in the Mortlocks and in Weno. Mar explained how much the memory of her childhood visits to the Mortlocks helped her appreciate her heritage and connection. These connections helped sustain Ray's family. Mar and Ren relied on their families to put together funding to send the four members of their family, including Baby Ray, to Hawai‘i. When they arrived in Hawai‘i, Ren's family sustained them, even though the family faced threats of eviction from their public housing units. Mar and Ren's family moved in with three different families before they ended up in the shelters. Their relatives also provided support to take Mar and Baby Ray to initiate his medical appointments and their engagement with the social services at the clinics. They provide periodic transportation needed for Ray's appointments. In return, Mar and Ren are active members of their family network such as the funeral insurance, birthday parties, and fundraising. Mar also provides help for relatives who arrived recently to seek medical assistance, and those in the hospital. She gives transportation support to assist other relatives in need.

Betty's identity with her Mortlockese heritage and identity remained with her as she navigated her new life in Hawai‘i. When she decided to bring Faith to seek medical help in Hawai‘i, her parents and relatives in Hawai‘i raised the money to pay for the airfare for Betty

and her three daughters, including Baby Faith. Her sister provided them with a place to stay until they were evicted from their apartment. She also provided initial assistance to Betty by taking her and Baby Faith to the clinic to start the medical appointment process. Other relatives helped her with transportation and assistance when the sister was not available. Betty and her family now participate in other activities such as birthday parties, fundraising, and church events.

All three families understood the importance and value placed on their identity and heritage. These identity and heritage connections provide support in times of great need, when the health and survival of their children and babies are beyond their individual capacity to handle. They are strong members or components of these extensive networks. They know their roles and the value of their participation to give back to the network that has been supportive of them.

Family Resilience

The second outcome highlighted in this study is the resilience and determination of the families to survive and contribute to their communities. These families are resilient and determined to provide the support their children need to survive and enjoy their lives. Beyond this basic survival of their babies and their families, they are determined to contribute to the communities that sustained them.

These families experienced a great deal of challenge with seemingly insurmountable barriers beyond their capacity to survive. Yet, they continued to survive through their hard work and dedication. They faced the risks of permanent dislocation on a near daily basis. They ended up living in homeless and transitional shelters. They are not eligible for the traditional full support of the safety net programs designed to assist these low-income families get on their feet and out of poverty. Yet, they continue to persevere.

The mothers take care of their children and elders in the families. They manage their children's medical appointments and education. They attend IEP meetings and learn from medical and social services professionals about their children's needs and strategies to meet those needs. They take their children to church services and activities. Two of these mothers are working and contributing to schools and children in those schools. Rita had offered to volunteer as an Educational Assistant in her son's school. Their husbands have been gainfully employed since they arrived in Hawai‘i, sometimes working two jobs at a time.

These families have worked hard to overcome the barriers they faced in search of the support needed for their children with special needs. They do so without full support from their government at home or the government in their new community in the US. These families are determined to survive and contribute to others.

Inclusion

The third outcome is the inclusion and nurturing support of these families for their children with a disability or special needs. It is strongly evident in this study that these parents love their children and they do everything within their capacity, and the capacity of their family networks, to meet the special needs of their children. Their children's disabilities and special needs bring out the caring nature of the family. These children are included as another cherished child of the family. Even though these needs may have severely challenged the families and put them through very challenging situations, it also strengthened the resolve and resilience of each family. These families feel no shame in having a child with a disability. Disability may be viewed as any other form of illness, a universal part of the human condition. All children are beloved members of the family, no matter the ability or disability. They are children and, like all family members, are a valuable part of the family network, "a gift from God," and are welcomed

in community. Children with disabilities are not left behind or hidden away at home. They participate in church and community events. Inclusion begins at home and in community. These parents also care about their children's education and participate in school activities and other education-related events. They want their children to be fully included and receiving an appropriate education.

Cultural Continuity

The final outcome that comes through vividly from this study is the appreciation of the support that these families received and the optimism of cultural continuity they show as they continue to navigate their daily lives in their new community. As an act of cultural nurturing, the three families received support from their own family members and others who have recently become part of their lives in Hawai‘i. All three families received financial support from family members, in Chuuk, Saipan, and Hawai‘i, to be able to bring their families and their children with special need to Hawai‘i. While here, they relied on their relatives to orient them to the services they needed. Their families sustained them when they move abroad to Saipan, Guam, and Hawai‘i. They took them in and provided shelter, food, and even monetary resources without any expectation of reimbursement.

They engaged in the cultural practice of reciprocity by giving back to their networks of support by participating in family activities and providing support to others. This culture of reciprocity persisted through these acts of support by family members for each other. Other people—newly encountered individuals, such as friends and allies, who are incorporated into the network—are vital to this cultural continuity.

It would be a mistake to interpret the experiences of these families as that of "victimization" or "loss." These are resilient families with dedicated and dependable support

networks of families and friends. They continue the ancient tradition of movement and travel as they navigate the turbulent aspects of their lives in Hawai‘i. They do so with their traditions of reciprocity and cultural continuity.

Family Themes

In the cross analysis of the themes, I laid out three sets of individual family themes that, when considered together in the indigenous perspective of Islanders' concepts and traditions of network and travel, can help explain and situate these families' experiences of travel from their homes to Hawai‘i. These themes explain the participants' identities, the endurance of hardship these families and their network had to go through in their daily lives, and their responses to the hardship through inclusion and nurturing.

Muir: Identity, Faith, and Courage

Muir. Muir is the tradition of fixing the direction of one's travel based on origin, which is essential in understanding the motivation of moving abroad by these families. Here muir denotes home, the physical and spiritual place that connects and guides travelers. It is the place that connects travelers to their identity.

Identity. The concept of identity is essential in this connection. Their identity is "who they are," "where they are from," and the places and people to whom they are connected. The identity of the family members interviewed in this project is strongly connected to this place of ancestral origin, whether it is told in stories or sung in songs. This identity maps the relationships they have with the island, the people, and knowledge and tradition. It is a strong connection that will prove useful throughout their experience in traveling abroad.

Faith. Faith is the true belief in the identity of their families and ancestry. It is this faith that also perpetuates their relationship with their spiritual world, their ancestors, knowledge,

genealogy, and, recently, in God and Christianity. To these families there is very little discernable boundary in terms of believing in both the power of their ancestral connection and their faith in God and Christianity. It is also in this faith that the strong devotion to the connections and relationship with their kinship networks is also found.

Courage. Courage is defined as the ability to sustain and utilize the faith in their identity in times of need and crisis. Courage is to be able to realize your situation and identify its solution from the body of relationships and connections to which you belong as a person. With strong courage, Islanders are never lost, even when they go to new places, as long as they are able to identify the relationship that they have with elements of the environment.

The grandmaster navigator Mau Pius Pialug explained this connection of identity, faith, and courage in the documentary film, *The Navigator: Pathfinders of the Pacific* (1983). Pialug, speaking through first-person narration in the film, explained the importance of having faith and courage in one's identity. He spoke of the importance of the revival of navigation for the Hawaiian Polynesians, "The Polynesians used to navigate the way we do today, without instruments or charts. They had *faith* in the words of their fathers." Then he extolled the special virtuous relationship between the faith one must have in the ancient knowledge and the courage to put oneself in the hands of the faith of that knowledge. "This is what we call *courage*. With this *courage*, you can travel anywhere in the world and never be lost." He related that faith and courage to his own ancestral knowledge, "because I have *faith* in the words of my ancestors, I am a navigator. *I learned these words as a young boy in the canoe house."* (my emphasis).

The families' Muir. When the health of their child or newborn baby was critically threatened at home, it became a crisis that disrupted the entire family throughout its network. The family had to find the solution within its identity, drawing upon the strength and resources

of it network, to enact a solution to this life-threatening crisis. In all three cases, the families had not planned to move to Hawai‘i until they learned it would be impossible to address the health of their babies through the local medical and healthcare system at home.

Rita and her family made the decision to move to Pohnpei for her to have her first baby. This decision was the result of their lack of trust in the healthcare system in Chuuk. That same healthcare system was also unable to handle TJ’s severe health challenges, including chronic kidney stones. Baby Ray’s health became a concern for his parents especially with the lack of information from medical officials at the Chuuk hospital. After consulting with the Healers Hospital visiting team they decided they had no other option but to move to Hawai‘i for a chance that Baby Ray may still live. Betty made her informed decision that she needed to take Faith and half of her family to Hawai‘i because the medical system in Pohnpei was not equipped to address the fragile health needs of Faith.

TJ’s family eventually moved to Saipan for TJ to have surgery. Rita received support and advice from family members who were medically knowledgeable, and her sister. All three families were unable to receive financial support from the FSM government to assist with the cost of attaining medical services off-island. TJ’s aunty brought Rita and Phillip’s family to Saipan. Their family also put together enough money to send Phillip and children from Guam to Hawai‘i to rejoin Rita and TJ. Ray’s family received support from their relatives in Chuuk. Faith’s grandparents and relatives initiated a series of fundraisers to pay for their airfare to Hawai‘i. All families utilized their family network to address these disruptive forces that threatened the lives and survival of the newborn members of their families.

Matauen Apungurosh: Existential Insecurities

The second set of themes, generalized as existential insecurities, is described by another navigational concept of Matauen Apungurosh. In this traditional concept of matauen (ocean of) apungurosh (dark), nothing is familiar or no one is enlightened. It is the concept of traveling strange waters, or uncharted waters. Apungurosh literally means *to be in darkness.* So, put together, matauen apururosh—as used here, means *to be in a strange place.*

In the three families' travels there were risks. Risks came in many forms and obstacles and in the unknown factors of barriers, which would challenge the capacity and ability of the network to solve. First, special healthcare needs of the children with disabilities were difficult to support and address in their home island healthcare system. This crisis took the families into unfamiliar territories in terms of family care. Second, the housing issue in Hawai‘i was especially difficult. The first two families lived with family members several times before they moved into the shelters. Even transitional homes were inappropriate for the size of these families and the specific needs of the children with disabilities in these families. The third family lived with family members in their apartment until their landlord evicted them. Finally, the lack of access to appropriate services and misconceptions about Micronesians in Hawai‘i contributed to the negative experiences and outcome for these families. In the first two families, the fathers were working more than one job just to provide the basic needs for their family. Even though their incomes were far below the poverty level, these families were ineligible to benefit from safety net programs such as food stamps and Medicaid, unlike other non-COFA immigrants. This lack of access to basic public assistance put major strain on the limited financial resources of these families.

It took strong faith to trust and rely on the knowledge and connections within the physical and spiritual repertoires of the families' networks to overcome these risks. This stubborn faith in hanging onto your identity in the face of challenges is what is interpreted as courage by traditional systems such as navigation.

Achu Matau: Inclusion and Nurturing

The final set of themes is the concept of inclusion and nurturing. It is the traditional navigation of figuratively connecting oceans: Achu (to connect) Matau (ocean). The strategy or tactic of conceptualizing and mentally visualizing, as a group, the isolated units of landmarks' ocean-areas, celestial bodies and their movements, and signs of wayfinding markings (eg. certain birds, schools of fish and other marine life, etc.), identifies new directions and resources. In the cases of these families, they forged new resources and direction out of old and new relationships, in order to provide assistance for their children with special needs in their new lives in Hawai‘i. In other words, the new strategies they formulated to address these barriers held together their new identities.

The family network may be overwhelmed which leaves the family vulnerable, but the family also recovers and the network becomes stronger by turning these incidences of vulnerability into positive assets. They do so by incorporating support and assistance from other family members and others who have come into their lives during their stay in Hawai‘i, such as medical professionals, teachers, and other social services providers.

In all three families the inclusion and nurturing began with the birth of each child with special health needs. The fact that they have special needs made them more special to each family in that they require more care, love, and attention by the parents, family members, and others who come into their lives. The parents love their children and include them in family and

other activities. As parents, Rita and Mar cared about their sons' education, but they care just as much about their safety at school. The focus of Rita's concerns with TJ's school experience was the incidents of safety and proper care TJ was getting at school. Mar did not want her son to be treated differently or excluded from school fire drills because of his disability. Ray is involved in all aspect of his family's activities: parties, church, fundraising, and movie outings. Both TJ and Ray are well known to service providers. Ray knows the Healers nurses and doctors who love working with him. Faith's mother takes her to family picnics, church services, and fundraising. Shelter staff and the other families, loved to play with Faith when they were staying at the shelter. Faith's grandparents and her oldest sister watch her when Betty is working in the morning or running errands.

Another aspect of the inclusion and nurturing cross-case theme is the role the mothers and their family played in providing care, inclusion, and nurturing to others in their family network, the schools, and the communities. This highlighted the strength and empowering effects of these migrant families. First, these families were hardworking people. The husbands, Mar, and Betty are employed. Ren and Phillip have had steady jobs since they arrived on island. Sometimes they worked overtime and faced difficult circumstances with transportation.

Second, they contribute to their family network. Rita and Mar actively support relatives and friends who are newcomers to Hawai‘i by taking them in and assisting them with medical and social services appointments. The three mothers are active members of their church and prayer groups. They contribute and participate in family and network fundraising. Finally, these mothers are active in their children's schools, and Mar and Betty are employed in the school system. Mar's work with ELL students is commendable and recognized by the school. Betty has utilized her education background to organize her children's appointments, not just with the

medical clinics and hospital visits, but their schools as well. She learns from the visiting therapists and had considered furthering her education in the special education field.

Research Questions

I started this study with the overarching research question that asked about the experiences of recent migrant Chuukese families of children with special needs living in Hawai‘i. I began with examining the *motivation* of Chuukese families of children with special needs to move to Hawai‘i. Then I looked at the *barriers* that these families face in their daily lives in Hawai‘i. Finally, I also examined the perceptions about the *quality of support and services* available to these families. In this section I will revisit the research questions in light of the data from the case studies.

Family Motivation to Travel

All three families were living their lives in FSM and had not planned to move to Hawai‘i until the health of their children became critical. Ray and Faith’s parents’ decisions to move to Hawai‘i were made just months after the birth of their babies and onset of their special healthcare needs. TJ actually spent his first nine years living with his family in Weno and the Mortlocks until his well-being was severely challenged by chronic kidney stones. All the families struggled at home trying to work with the medical systems, clinics, hospitals, and traditional remedies, before they ultimately made the decision to go off-island to seek medical help for their children. TJ’s parents moved to Saipan and TJ received appropriate surgery and treatment. It was not until their second appointment with Healers Hospital in Honolulu that the decision was made to move the family to Hawai‘i to support TJ’s ongoing medical treatment. Similarly, Ray’s parents had consulted the visiting Healers Hospital staff in Chuuk to fully understand the extent and need for Ray to be taken to Hawai‘i for proper treatment. Faith's mother consulted her baby’s doctors at

the clinic and was given the advice to take Faith off-island to either the Philippines or Hawai‘i to seek more specialized treatment for her condition.

The first set of barriers encountered or experienced by these families was the lack of medical support for their children at home. Each family experienced some measure of stress at the early stage of their babies' lives when the realization of the special needs for their children began to set in. TJ's parents noticed that the baby was not passing urine regularly and seemed agonized and cried all the time. It was not until the doctors operated on TJ to alleviate the urinary track blockage that the parents were able to experience momentary relief. For baby Ray, the issue of a lack of communication from the local physician to properly inform his parents about his condition, was a great source of stress. For eight months his mother witnessed the deteriorating health of her baby without any clear information about his conditions. They tried local traditional remedies but those didn't help either. Betty experienced difficulty with her pregnancy and with the birth of Faith. When the baby was born and the doctors gave her the prognosis of hydrocephalus, Betty was initially in denial until she witnessed the changes in her baby's growth. All of these instances of these parents' encounters with their children's disability or special needs and the associated barriers, caused initial stress in the lives of their families. However, these families rose beyond these challenges and moved on to seeking support and assistance to help their children. They did not succumb to the threat or barriers brought on by these challenges.

It is evident that with the onset of these children's disabling or special needs conditions, their families struggled to find treatment and medical solutions to keep them alive. These incidences are matters of life and survival and required these families to leave home in search of life-saving treatments for their children and babies that are unavailable in the FSM. These are not

stories of weaknesses; rather it was the strength of these family networks to act beyond the capacity of governmental systems that offered support to the special needs children.

Barriers

The barriers that threatened the resiliency of the families and their network of support had to do with the access to housing and proper resources while living in Hawai‘i. Homelessness was an incredibly challenging problem. All three families moved from place to place, between relatives’ apartments, shelters, transitional homes, and finally into permanent housing. For TJ and Ray’s families, it took years for these families to be settled in proper public housing, which are compatible and consistent with their levels of income. In the third family’s situation, the challenge is still an ongoing barrier. Moving from their relatives’ place to a shelter, they are back to living together with other members of their family network to share the cost of private rental housing.

Related to the issue of access to housing, these families continued to struggle with limited access to social services. Since they are not U.S. citizens, they are ineligible for the food stamp program and other assistance such as Medicaid. Instead, they are enrolled in costly private insurance through the Affordable Care Act (ACA). These insurance coverage plans require monthly premium payments and other coinsurance costs. These mothers’ coverage has been discontinued several times due to nonpayment penalties. These penalties affected their financial credit, which means they face continued barriers to securing private rental apartments because of their negative credit scores.

In addition to the limited access to social services, these families also have faced misunderstandings and negative stereotypes by service providers. TJ first experienced the racist treatment by his Educational Aid in Saipan. When the family moved to Hawai‘i, Rita also had a

difficult time with her son's school IEP team in their lack of understanding of the challenges she had to overcome in order to regularly and properly participate in her son's IEP meetings. At times, there were no interpreters and she would not sign the IEP form. The school counselor scolded her about not taking care of her children when she clearly had difficulty managing her parental obligations without transportation support. Ray's mother was clearly upset about the treatment her son received during the fire drill at school. Even though she did not want her son's disability to be a factor in his treatment by school officials, Ray's teacher decided to exclude him from participating in the fire drill. Betty's overwhelming concern about being homeless and living in the shelter was exacerbated by her social worker's negative stereotype that Betty might not like living in the shelters because there were "lots of Chuukese [at the shelter]."

These barriers experienced by the parents of these children with special needs created strong elements of stress and negative challenges for these families and their networks of support.

Perceptions of Social Services

There was a common perception among the first two mothers that the school officials, although knowledgeable about educational teaching, lack a strong nurturing care for their children. Rita's experience with TJ's Educational Assistant in Saipan had profound effect on her perception about school personnel and their level of care for TJ. These concerns were not unfounded. Several times Rita complained about mishandling of TJ's care and his wheelchair by school staff. During IEP meetings, Rita complained about the lack of attention and support the staff displayed for her son. Mar also complained about lack of care for Baby Ray by his teachers who excluded him from school activities because of his disability. At the same time, both Rita and Mar noted the helpful services that their family and their children received from other

service providers, such as the preschool teachers, community clinic social workers, and shelter officials.

With proper support from family members and service providers, these families are thriving and actively participating in their communities and in the lives of their children with disabilities. Faith enjoyed the love and attention of her sisters, other kids at the shelter, the shelter staff, her grandparents, and others who interact with her in the public events she had been taken to, such as family fundraising, birthday parties, and church activities. The service providers such as the shelter staff, the physical and speech therapists and audiologists, the preschool teachers, public health nurses, and clinical and hospital staff are also included into Faith's families' network of friends and support.

Methodological Approach

This section will address this qualitative study's methodology by examining the use of the case study approach, the interview and focus group process. It will also consider the triangulation, representativeness, and generalizability of the study to address the issues of internal and external validity.

Case Study

Yin (1984) and Tellis (1997) explained that the case study, as a method of qualitative studies, is effective in interpreting multiple layers of meaning of experience from different and multiple sources. In this case study the three families are the units of analysis, whose experience with the critical phenomena of meeting the needs of their children with special healthcare needs required not just multiple sources of information but extensive engagement with these families in order to understand their experiences. The decision to utilize the case study model for this project

was rooted in a commitment to showcasing the multiple points of view and sources of data in order to understand the families' backgrounds, experiences, and perceptions.

As much as I have prior knowledge about, and connections with, these families, it was important to establish a strong relationship, one that is necessary for them to understand the purpose of this dissertation and fully support the goal of the study. Their involvement in the project is based on their trust that this study will support and help other families with similar needs. This was evidenced by how these families became helpful and supportive to each other, and the broader community. It is also part of our relationship in the work that I do in the community and a connection based on the fundamental concept of cultural reciprocity and relationship. When these mothers listened to me re-telling the story of my sister Kutelia and her son Jon, about how my family struggled to meet Jon's needs, they understood my sincerity and the integrity of the study; and they believed in the value of the stories and their contribution.

We also interacted in many events and activities such as having lunch and barbecue at one of the families' places, going to movies, attending church activities, and engaging in family events, before we started conducting the interviews. The semi-structured interviews were designed to follow the Chuukese tradition of aporous or telling and re-telling stories. It was not undirected or pointless conversation. There were purpose in allowing the parents to feel comfortable and compelled to share their stories.

The use of Case Study methodology helped explore the deep and multiple experiences and meanings of these families' lives. It allowed for me, as the researcher, to participate in the families' daily experiences with the issues they faced on a regular basis.

Focus Group

The focus group discussions were very productive. Liamputtong (2011) pointed out that focus group is especially effective in ethnic minority groups because it allows participants to feel encouragement from each other's participation in the group discussion. The families were able to listen to each other's stories and articulate similarities and differences in their experiences. As a strategy, it was obvious that the participants felt comfortable sharing their own stories when they heard the others' stories and realized that they were not alone in their experience. They recognized the common experiences and appreciated the uniqueness of each individual's stories. Since the first two families arrived and stayed the same length of time in Hawai'i, they were able to share their stories with the third family, which had just arrived in January of 2017. In this way, the two families felt that they were being helpful to the third family, especially since the mother in the third family is a few years younger than the other mothers. The focus group was effective in engaging the families in telling and retelling their stories among each other. It validated their experiences and also made them feel appreciated.

Limitations

The obvious limitation of this study is inherent in the qualitative case study method that was used. The study focused on three families from similar ethnic and linguistic backgrounds. There should be some caution about extending and generalizing the result of this study across different populations. However, the small number of participants also allowed the researcher to focus and explore in depth the experience of these families. I will discuss these inherent limitations in the representativeness and generalizability of the data and results of the study.

Representativeness

The family experiences shared in the stories have strong similarities but also individual features. They feature the strong family network that is caring and supportive. Their children are part of this expansive network and they are loved and cherished just like every other child in these families. Their travels took several different routes to Hawai‘i. TJ and his family went to Saipan and Guam before coming to Hawai‘i. Ray’s family came directly from Weno, Chuuk. Faith and her family lived in Pohnpei before coming to Hawai‘i. Their families’ experiences with housing and medical healthcare had a common source or origin, rooted in the immigration designation under the Compact of Free Association (COFA).

I cannot really say if the families’ experiences are representative of other, non-COFA immigrant populations. There is a marked difference in the immigration status of COFA citizens that differentiate their experiences from other immigrant groups. This, while allowing their unlimited travel to the US, limits their eligibility for social services compared to other immigrants. While there is some room for the study to be considered as a representative of similar families within the COFA population, such representativeness may not apply across broader immigrant and ethnic groups.

Generalizability

Generalizability is the ability to apply findings to other populations (Merriam, 2002). In this study I focused on three families from Chuuk who migrated from their homes in Micronesia to Hawai‘i to seek support in the healthcare system for their children with special needs. The results may or may not be applicable to other families of children with special needs with similar backgrounds.

Implications for Theory and Research

For this study, I relied on three different, yet related, theoretical frameworks that, when considered together, would better explain about the experience of these migrant families of children with disabilities. I do not imagine the three theoretical frameworks in isolation. I view these three as being merged and connected: Family System Theory, Family Resilience Theory, and FQOL Theory. Family System Theory is based on the assumption that all members of the family play an interconnected role in the way the group functions together (Bowen, 2007) and that the family members' relationships with each other are critical in understanding and solving problems and issues for members of the family. The domains of the family (Summers, Brotherson, & Turnbull, 1998) include its structure, interaction, functions, and lifecycle. These domains make the family goal-oriented, self-correcting, dynamic, and interconnected (White & Klein, 2002). The family networks, to which the Mortlockese families belong, are dynamic and interconnected. These networks have expanded and grown beyond the islands. Its members have expanded the structure to Pohnpei, Weno, Saipan, Guam, Hawai‘i, and several states on the mainland US. Members of these networks interact with each other on a regular basis and dynamically through travels, exchange of goods, and even though the social media, which connect these locations including the small islands in the Mortlocks. When these children with special needs were born into these family networks, it touched everyone's life in this network; everyone is there to help and contribute. These special needs children are not left behind and their families are not alone to fend for themselves. I employed the traditional concept of *Muir* to highlight the vantage point within these expansive networks, from which the purpose and starting point of these travels have been undertaken. The *Muir* in these cases is both the home islands and

the children with special needs. They are the starting point (steering point) and the reasons/purposes for the family travels.

Family Resilience Theory describes families undergoing a period of vulnerability and stress during a crisis but eventually emerging "stronger and more resourceful" to face the future (Smith 2003). The shift in recent iteration of the Family Resilience Theory has moved away from focusing on the individual—in the case of this study, the children with special needs—to the broader family network and structure. The children are not left behind and their disabilities are not the focus of resiliency in this study. Their families are not scrutinized in isolation to examined instances and evidence of their resiliency. Rather, the aspect of family resilience focused on the families' interconnectedness with the networks to which they belong, and from which they draw support. This study also employed the traditional concept of Matauen Apungurosh*,* which describes the risks and instances of vulnerability when the family networks are tasked beyond their capacity. These risks included the birth and initial realization of the children's special needs and disabilities, the means to provide financial support to move these children and their families to Hawai‘i, the challenges and anxiety of urban living in Hawai‘i, poor access to medical care, unsympathetic school staff, and housing challenges, amongst others. In spite of these challenges, the families are persevering and continue to provide love and care to their children with special needs and their extended families.

Like Family System Theory and Family Resilience Theory, FQOL examined the quality of life beyond the individual—the children with special needs—to consider the quality of life of the "family" as a broader unit of analysis. Starting with expanding the definition of "family," researchers considered the members of the family to be anyone that the family itself would define as its member. This would include friends, who are important to the family, and

advocates, who are incorporated into the family (Poston et al., 2003; Turnbull, Turbiville, & Turnbull, 2000;). FQOL took into consideration the interconnectedness of individuals to their families and the families to the network to which they belong. It would be misleading for this study to focus solely on each child's resiliency or define his or her perceived individual quality of life. It would not provide any information on their family and those important components of their network who provided important support to them. So, I also used the traditional concept of Achu Matau as a way to explore and explain the intricate network and meaningful experience that shaped the family stories. The concept, which literally means connecting oceans, gave appreciation and paid respect to of the dynamics and structures of these families' cultural heritage.

In conducting a research study utilizing three Western theories that explained the structure, engagement, and perception of life for individuals or children with disabilities and their families, I have also attempted to address these families' cultural perspectives and connections between these families' cultural and traditional backgrounds. I added elements of indigenous concepts to serve as a fourth dimension in the theory section of this study to be able to represent the perspective of the participants in the study. This is not just for the purpose of empowering their voices, but also to give proper respect to the modes and means of developing more culturally-appropriate research protocols and methodologies. There is a need for indigenous voices in studies of indigenous participants. The connection to indigenous theory is necessary to understand and appreciate the cultural phenomenon behind the experience of these three families from the Mortlocks, in their places at home and in their new home in Hawai‘i. The three concepts that I identified, or borrowed, from indigenous Mortlockese navigational concepts are Muir, Matauen Apunurosh, and Achu Matau. This narrative, or theoretical "borrowing," is

essential in order to pay respect in reciprocity to these Western theoretical models and, at the same time, maintain credibility and integrity of the Mortlockese indigenous concepts and stories vis-à-vis Aporous.

Future Directions for Research

Obviously there is room for further research. It would be interesting to continue doing research with a similar but larger sample population. There are several families from Micronesia with children with special needs who have moved to Hawai‘i for better services. Conducting a similar study to find out if the same results will be replicated would be fruitful towards building a body of literature on the topic of the experiences of COFA migrant families with children who have special needs in Hawai‘i. Another area where similar studies could be conducted is with Micronesian families who have children with disabilities who are born in the United States and are U.S. citizens. One of the critical aspects of the families in this study is that all of the children and parents in the households are non-U.S. citizens; therefore, they were not eligible for safety net programs to support their families. A comparison in outcomes between families of children with special need born in Micronesia versus those born in the US would be useful.

Implications for Practice

Hawai‘i is a multicultural, multiethnic society. It is essentially built on the diversity of waves of new people coming to its shores and establishing their place in this community. Micronesians from the COFA nations are the latest in these waves of newcomers to Hawai‘i. Their numbers in the schools are growing every year with students coming to the Islands, as well as those born and raised in Chuukese families here in Hawai‘i. I want to offer some recommendations from observations and the results of this study that can help service providers to be able to work more effectively with parents like those in this study.

The first recommendation is to pay close attention and show respect for the parents' cultural background. These parents may have left their home islands but it does not mean that they have left their cultures behind. They have their cultural heritage and ancestral connections. Service providers should not make inaccurate assumptions about these parents. One common assumption, for example, is that Micronesians all speak one language. There are over 27 languages spoken across the Micronesian region. Service providers may ask the parents what language they prefer for communication. They can ask questions about their cultural beliefs. For teachers to be effective in this multicultural educational setting, they have to be open-minded and aware of the different nuances of these students' cultural backgrounds. Teaching is empowering and teachers cannot empower students who they do not understand.

Another common false assumption about Micronesian parents is that they do not care for their children. This point may be easy to dismiss as not being a real issue that actually happens, but I have been in conversation and in official meetings where service providers would question the level of care that Micronesian parents have for their children. These stories show the level of parental and familial care that is bestowed on these children with special needs. Working closely and getting to know the parents will enlighten service providers about the cultural values of deep love and connection between parents and children, including those with special needs. Teachers will face parents such as these who struggle with many other aspects of their daily lives. Their roles and participation in their children's education is often affected by these struggles.

Finally, service providers should not underestimate the willingness of parents to participate in their children's educational activities. They want to give back to their communities and school, to reciprocate with good service providers. The three parents in this study were always willing to provide help with other families and their children's schools. This is good for

community relationships and it also helps getting these parents integrated and welcomed in the school setting.

These parents have a strong connection with their home culture. They care and love their children with special needs and are willing to help others and work with service providers to support and help to others. They want to give back and reciprocate, which is a major part of their culture and that helps affirm their own sense of connection to the schools and the clinics where their children receive treatment assistance.

Lessons Learned

The primary lesson is that the onset or occurrence of disability or special healthcare needs for a child may cause disruption in these families' lives and challenge the families and their networks of support. However, these families and their networks were resilient and, even though they have been through a lot of challenges, they were able to overcome these barriers and became empowered and willing to reciprocate and help others. These children with special needs were not left behind. They were loved and cared for even more so because of their special needs, by their families and those around them.

The second lesson learned from the study is the complicated experience of COFA migrant families in Hawai‘i. Since these families are classified under the immigration system as Un-Eligible Aliens, as citizens of the Compact of the Freely Associated States, they faced unequal access to the U.S. safety net programs that supports low income families.

Finally, the families were very generous and willing to contribute and guide the study. Once the mothers understood and developed trust in my integrity and sincerity to share my stories, they opened up and shared their stories. They understood that their stories would help others who have children with special needs and those who work with these children and their

families. That aspect must be understood and respected. To be effective in this type of qualitative study, researchers must be trusted to share their stories with the participants. The element of trust must be reciprocated with respect by researchers. Participants are very knowledgeable about their own issues and their point of view; their perspectives will often contribute more to the study than the researcher could anticipate. Participants in these studies that span over a long period of time, must be respected for their contribution. The timeline often set up by researchers must be flexible and accommodating.

Their stories were powerful and they kept reminding me about my own family's experience with Kutelia and Jon. In many ways, I shared, and continue to share, the painful experience, and also the celebration of the joy their children bring into their lives. My family's memories of my sister and my nephew has gradually eased from the painful recollection of our struggles to more positive and joyful memories of the happiness they brought into our lives. Undoubtedly, these family stories, and my own, have given me a positive affirmation for the work I do in our Micronesian communities in Hawai‘i.

CHAPTER VII: SUMMARY

This study set out to examine the overall experiences of three Chuukese migrant families of children with special needs as they travelled from their home islands to Hawai‘i. Their motivation to move to Hawai‘i, the barriers and challenges they encountered, and their perceptions about the services and support they received were explored through the stories they told and corroborated through focus group discussion, documentation, and the researcher's prolonged observation and own experience. Through the theoretical lens of Family Systems Theory, Family Resilience Theory, and FQOL Theory, the study addressed these research questions with substantiation from local Chuukese themes of travel, and the narrative strategy of aporous, or storytelling.

These Chuukese families described strong heritage and identity connections to their traditional network of relationships. Their networks spanned from their islands in the Mortlocks, their ancestral homelands, to places where their families and relatives had traveled and established homes such as Weno, Pohnpei, Saipan, Guam, Hawai‘i, and several locations throughout the mainland United States. In their times of need, these three families relied on their networks for support, guidance, and assistance. These families were also part of a phenomenon identified as recent migration of Micronesian citizens to Guam, Hawai‘i and the mainland U.S. They are labeled as COFA citizens from the Republic of Palau, Federated States of Micronesia, and the Republic of the Marshall Islands, and who migrated to the U.S., under a treaty between their countries. This COFA treaty gave these citizens open access to the U.S. but did not guarantee full access to the social services safety net programs in the country. This created barriers for these families in their daily lives in Hawai‘i.

The challenges and barriers these families faced are astounding. The onset of their children's disabling conditions and the lack of medical support and solutions in their home islands had compelled these families to uproot themselves and move to Hawai‘i. The lack of governmental support was notably stressful but in all three family cases, their own network provided the funding to enable these families to travel abroad for their children's medical care. They continued to face barriers in Hawai‘i such as homelessness and housing issues, lack of access to proper healthcare insurance, school-related challenges, discrimination, and employment issues. These networks may be stretched to their limits and get overwhelmed, but the families recovered and became empowered by the challenges.

These families were resilient and resourceful. They were engaged in their children's education. They participated in church and community events and activities. Their children with special needs were cared for and loved by their families and others who interacted with them. The children's disabilities motivated their families to be resilient and to work hard, reciprocate, and help others. They were productive members of the community in Hawai‘i.

APPENDIX A

UNIVERSITY of HAWAI'I MĀNOA

May 8, 2015

TO: Joakim Peter
Principal Investigator
Special Education

FROM: Denise A. Lin-DeShetler, MPH, MA
Director

SUBJECT: CHS #23077 - "Perception of Needs and Support Among Recent Immigrant Chuukese Families of Children with Disability in Hawaii"

This letter is your record of the Human Studies Program approval of this study as exempt.

On May 8, 2015, the University of Hawai'i (UH) Human Studies Program approved this study as exempt from federal regulations pertaining to the protection of human research participants. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.101(b) (Category 2).

Exempt studies are subject to the ethical principles articulated in The Belmont Report, found at http://www.hawaii.edu/irb/html/manual/appendices/A/belmont.html

Exempt studies do not require regular continuing review by the Human Studies Program. However, if you propose to modify your study, you must receive approval from the Human Studies Program prior to implementing any changes. You can submit your proposed changes via email at uhirb@hawaii.edu. (The subject line should read: Exempt Study Modification.) The Human Studies Program may review the exempt status at that time and request an application for approval as non-exempt research.

In order to protect the confidentiality of research participants, we encourage you to destroy private information which can be linked to the identities of individuals as soon as it is reasonable to do so. Signed consent forms, as applicable to your study, should be maintained for at least the duration of your project.

This approval does not expire. However, please notify the Human Studies Program when your study is complete. Upon notification, we will close our files pertaining to your study.

If you have any questions relating to the protection of human research participants, please contact the Human Studies Program at 956-5007 or uhirb@hawaii.edu. We wish you success in carrying out your research project.

1960 East-West Road
Biomedical Sciences Building B104
Honolulu, Hawai'i 96822
Telephone: (808) 956-5007
Fax: (808) 956-8683

APPENDIX B

Toropwen Omw Moutata omw kopwe fiti ei research ika pekin kaeo:

"Meefian Family en ekkewe semerit mi or terir seni Chuuk ren nonnomwur lon Hawaii."

Itei Joakim Peter seni ach we sukun University of Hawai'i. Ngang ua aucheani ai upwe tungor ngonuk ika kopwe fangfangeoch omw fansoun me omw alilis on ach ei project. Ai ei project fen iten sopwsopwun ai sukul ika kaeo.

Awewen ei Project: Met Epwe Fis me Taman om Fansoun Alilis: *if kopwe fiti ei project, kopwe chufengen men emen epwe anisuk ne panueni ekoch kapas eis fen itan ukukun omw weweeti ekoch porous ren nonomwun omw family me ar osukosuk me lon Hawaii. Ei interview ina epwe tori 30-60 minich tama new, nge epwe tufich sipwe porous ika chufengen fen ruu. Mi pwan tongeni ika aupwe recordini ena interview. Murin auwa makeiouw mosowan ena interview pwun aupwe study ni. Ika kopwe fiti ei men, mi pwan or 4-6 chon fiti ei pekin kaeo ika interview. Iei ew kapas awewe ren sokun kapas eis aupwe eisnuk, "met mefiomw ren met mi osuosuka noumw we semerit mi terin?"*

Eochun me ngfawan: *Esor tufich mine epwe awenewen ngonuk omw fiti ei inyerview. Nge mi chok or tufichin me annimen ei pekin kaeo epwe eochuno angangen aninis ngeni ekewe family en semerit mi kan or terir seni Chuuk ra nonomw lon Hawaii. Ach nukun nge ese pwan or feingawen omw fiti ei men nge ika en kopwe mefi riaffou me weires ren ekkei kapas eis, kich mei tongeni kauno ika asoso ika fen wesilo ika kose chuen mochen fiti ei angangen interview.*

Monomwonen omw fiti ei study: *Atun ei research mettoch meinis seni met mi mmaketiw me record on tape epwe lock no lon an ewe special education coordinator office. Esor me lukun ngang epwe kuna ika auseling met mi tolong lon ei research. Pwan chok ewkkewe chon University of Hawaii on ewe committee ekan nemeni tumunun ekei pekin kaeo repwe tongeni angei ika anea me ausening ren chon timunun ekei sokkun study.*

Ika auwa pwan makkei ika awesano met am angang ausapw tongeni pwarano itomw ika pwan ekkoch met aramas repwe sinei pwe en ewe ke uwatiw omw porous on ei study. Mi epwe nom lon am mak esapw awenewen ngeni emen aramas. Ika kopwe pwan mochen nouni copin am report ngang mi tongeni ngonuk ika ke kori ei on ena nampa mi affat me fan.

Omw fiti epwe volunteer: *Kopwe pwusin nemeni ika kopwe fiti ei studyika kosapw fiti. Ika ka fiti en mi pwal chok tongeni lemenata ika kosapw chuen sopwosopweno fiti ei study, esor met epwe fis ngonuk.*

Kapas Eis: *ika mi or omw kapas ei on ei study ka tongeni koriei on ei phone (808) 393-4235 ika fen mak ngeni ei on ei ei e-mail address (joakim@hawaii.edu) ika Dr. Mary Jo Noonan, noun nampa (808) 956-5599. Ika mi or om kapas eis fen itan om pwung ika an noum we semerit pwung lon ei study ka tongeni kori ewe committee a kan tumunu ekei sokkun kaeo me University of Hawaii of Hawaii. Phone nampa (808) 956-5007 ika e-mail uhirb@hawaii.edu*

Ka tongeni isoni ei toropwen atipeu. Ika en mi moutata om kopwe fiti ei project, kose mochen saini itomw on ena lenien sign iwe ka aniwini ei toropwe ei spoun ngeni Ansina Kony ka chok tongeni ngeni emen chienan kana chon angang.

Omw Signature ren ome moutata om kopwe fiti ei study:

" Ua moutata ai upwe fiti ei research project title in, ***"Meefian Family en ekkewe semerit mi or terir seni Chuuk ren nonnomwur lon Hawaii."***

Ngang mi weweiti pwun ngang mi tongeni asinei ngeni ekkei chon fori ei ika inet chok uwa mochen kauno seni ai fiti ei study inet chok uwa mochen.

Kopwe makei itomw: _____

Kopwe sain on ei line ika en mi moutata_____

Date: _____

Kopwe pwal checki “u” ika “apw” ika en mi tipew ngeni an ei chon interview epwe tape ni ika record ni omw porous:

“U”_____ ika “apw” _____

iwe ika en mi tipew ngeni ika ke check “U” (*Pwan ngang mi weweiti pwun kopwe pwal tongeni recordni ach interview, mi ok me rei.) iwe kose mochen kopwe sign me fan:*

Signature: _____

Agreement to Participate in

Perception of Needs and Support Among Recent Immigrant Chuukese Families of Children with Disability in Hawaii: A Qualitative Study

Joakim Peter

The purpose of the project is to learn what factors affect families' perception of needs and access to services for their family members with special health care needs. You are being asked to participate, because you have a child with special needs and you are from a Freely Associated State (FAS), specifically from Chuuk.

Participation in the project will consist of an interview with one of the research team members. Interview questions will focus on the daily experience and stories about challenges and needs for services for your family and your child is receiving. Data from the interview will be summarized into broad categories. No personal identifying information will be included with the research results. Each interview will last approximately 30 – 60 minutes. It is expected that there will be two interviews for each participants. Approximately 4-6 families will participate in the study. Interviews will be audio recorded for the purpose of transcription.

The investigator believes that there is little or no risk to you from participating in this research project. However, there may be a small risk that you will experience psychological pain when closely examining your experiences of getting health and education services.

Participating in this research may be of no direct benefit to you. It will not affect the services that you are receiving. It is believed, however, that the results from this project will help improve health and education service providers' understanding of how to help individuals like you get access to services.

Research data will be confidential to the extent allowed by law. Agencies with research oversight, such as the UH Committee on Human Studies, have the authority to review research data.

All research records will be stored in a locked file in the primary investigators' office for the duration of the research project. Audio recordings will be destroyed immediately following transcription. All other research records will be destroyed upon completion of the project.

Participation in this research project is completely voluntary. You are free to withdraw from participation at any time during the duration of the project with no penalty, or loss of benefit to which you would otherwise be entitled.

If you have any questions regarding this research project, please contact the researcher, Joakim Peter, at (808) 393-4235 or Dr. Mary Jo Noonan at (808) 956-5599.

If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808) 956-5007, or uhirb@hawaii.edu

Participant:

I have read and understand the above information, and agree to participate in this research project.

_____

Name (printed)

_____ _____

Signature **Date**

_____ I agree to have my interview audio recorded.

Initials

_____ _____

Signature **Date**

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